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ABSTRACT

This book examines disability related housing and support services in Canada. It describes the major sources of funding supporting these services and analyzes associated problems. A variety of policy options for improving the availability and quality of disability-related housing and support services is offered. The first chapter briefly describes the focus of the study and the second one describes funding arrangements including funding auspices and methods of transferring funds. Covered in chapter 3 on funding sources are programs funded by the Canada Mortgage and Housing Corporation (e.g., the Residential Rehabilitation Assistance Program, the Rent Supplement Program, the Non-Profit Housing Program, and the Cooperative Housing Program); the Canada Assistance Plan; and other established programs. Discussed next is the interaction of funding sources. Chapter 5 provides an analysis of such topics as fragmentation of service, restrictive criteria, rigid rules, lack of service, residual orientation, service income linkages, administrative barriers, attitudinal barriers, standards, lack of control, lack of privacy, and need for changes. Chapter 6 identifies policy options in the areas of affordable housing, support services, and personal supports. Recommended are more funds for the provision of generic services, increased funding for housing assistance programs, and restructuring of funding arrangements. (DB)

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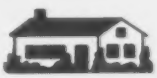

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ERRATUM

Page ii, second paragraph, first sentence should read:

The result is a set of parallel services and programs that were initially set up as charity but that are now in fact paid for out of the public budget.

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The G. Allan Roeher Institute

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Canada's National Institute for the Study of Public Policy Affecting Persons with an Intellectual Impairment

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- to identify and anticipate future trends that will support the presence, participation, self-determination and contribution of persons with an intellectual impairment in their communities;
- to foster the exchange of ideas leading to new ways of thinking about persons with an intellectual impairment.

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Table of Contents

Foreword i

Introduction 1

Chapter 1: The Focus of this Study 3

Chapter 2: Funding Arrangements 9
- FUNDING AUSPICES 9
- METHODS OF TRANSFERRING FUNDS 13
  - Transfers 13
  - Taxes 14

Chapter 3: Funding Sources 17
- CANADA MORTGAGE AND HOUSING CORPORATION 17
  - Residential Rehabilitation Assistance Program 18
  - Rent Supplement Program 19
  - Non-Profit Housing Program 20
  - Cooperative Housing Program 25
- CANADA ASSISTANCE PLAN 29
  - Assistance Provisions 29
  - Welfare Services Provisions 31
- ESTABLISHED PROGRAMS FINANCING 38
  - Extended Health Care Services 44
  - Provincial Initiatives 51

Chapter 4: The Interaction of Funding Sources 55

Chapter 5: Analysis 67
- FRAGMENTATION OF SERVICE 67
- RESTRICTIVE CRITERIA 69
- RIGID RULES 70
- SQUARE PEG SYNDROME 72
- NO PORTABILITY 73

LACK OF SERVICE 75
RESIDUAL ORIENTATION 76
LINKING SERVICE TO INCOME 78
ADMINISTRATIVE BARRIERS 80
ATTITUDINAL BARRIERS 82
COMPETITIVE PROCESS 83
ABSENCE OF GUIDING PRINCIPLES 85
ABSENCE OF STANDARDS 86
LACK OF CONTROL 87
LACK OF PRIVACY 89
NO RECOURSE 89
NEED FOR CHANGE 92

Chapter 6: Policy Options 93
PRINCIPLES 94
Inclusion 94
Citizenship 97
Self-Determination 99
FROM PRINCIPLES TO PRACTICE 101
Housing 102
Supply of Affordable Housing 103
Demand for Affordable Housing 105
1. Rent Supplement Program 105
2. Tax Credit 107
3. Improved Welfare Benefits 107
4. Assistance for Modifications 108
Support Services 110
1. Redirection of CAP/EPF Funds 111
2. Canada Assistance Plan 113
3. Established Programs Financing 115
4. Canada Mortgage and Housing Corporation 116
5. New Cost-Sharing Arrangements 116
6. Individualized Funding 117
7. Family Supports 121

PERSONAL SUPPORTS 123
Personal Support Networks 123
Brokerage 124
Advocacy 125
SUMMARY OF POLICY OPTIONS 128

Conclusion 131

Notes 133

FOREWORD

Poverty is a way of life for people with a disability in Canada. In the 1990's in one of the richest nations of the world that this should be the case is shocking. In our efforts to understand the underlying causes of this poverty — the lack of economic and social integration — The G. Allan Roeher Institute has undertaken a number of policy studies which look at the root of this problem and offer policy options that can address the systemic causes.

These studies dealing with such issues as income support, employment, literacy, education and training, and housing and support services begin to address the need for an overall disability framework to ensure full citizenship for persons with a disability. Each of the studies is part of an overall re-evaluation of the place of persons with disabilities in Canadian society.

To address citizenship we have to start by recognizing the connection between collective goals and what a society grants as a matter of right to its individual citizens. Social policy, economic policy and health policy must address explicitly what individuals should be enabled to do for themselves and for others. This requires a new context for political debate about policy responsive to disability. The alternative is to continue to tinker with the programs and policies in place. The overall impact of this tinkering is that few individuals with disabilities participate in the mainstream and there is no real recognition that our society genuinely includes people with disabilities. In other words, tinkering will do little to change the basic message that is being conveyed about persons with disabilities, namely that they are peripheral members of the community who can participate when it is convenient or practical to fit them in. While it may be helpful to have "disability" programs and policies in the short run, such policy in the long run is likely to further segregate and isolate people within a separate but unequal model. What we need instead is a framework for policy that is progressive enough to recognize that those with disabilities are part of the population that any policy must be designed to meet.

The problem that we have uncovered in looking broadly at disability is that most of the programs and policies that are in place were established as add-ons to programs that did not have the issues involved

in disability in mind when they were conceived. Historically they began with assumptions that people with disabilities would not be a part of the mainstream of society. Consequently, the structures established — the education system, the labour force, the economic structure, the income programs and so on — were not designed to deal with a population that would have been inclusive of those with disabilities. Now that it is becoming evident that people with disabilities ought to be full participating members of society, it is very difficult to accommodate them within the traditional institutions and structures. In most cases, the result is a series of social and economic programs that have an add-on to deal with disability. There has been no major restructuring of the system to enable them to be a part.

The result is a set of parallel services and programs that were initially set up as charity but that are not in fact paid for out of the public budget. The establishment of parallel or tag-on systems of transportation, education, employment, housing or recreation suggests an inappropriate frame of questions. Rather than asking what is wrong with the existing policies that they do not fully include those with disabilities, questions are now being raised about how people with disabilities can have access to existing programs. In other words, an assumption is made that it is possible to tinker with the existing structures and this will meet the needs of those with disabilities. We have found in our research that this is not possible primarily because it always leaves the person with a disability in a defensive position. If, with whatever minor adaptation is made, more of those with disabilities fit in, arguably the social and economic structure will continue to be considered acceptable. If the basic structure is not changed, however, then the person with a disability will always be marginal, always in some way a lesser citizen, pleading to be taken seriously by the rest of society. The cost is both social and economic.

We are attempting to in our studies to examine critically this approach to disability and the way in which public policies and programs have been structured. At present, eligibility for and entitlement to social benefits are treated as social privileges to be distributed on a discretionary basis to select target populations that can establish personal "merit", rather than as matters of an individual social right guaranteed on the basis of clearly defined conditions, or as an ethical imperative binding the state/community at large to the individual in need. The needs of persons with disabilities should not, however, be thought of as special needs, any more than the needs of those without

disabilities might have been seen as special had those with disabilities designed the world initially. If the needs of one disadvantaged group are seen as special, they become pitted against the needs and rights of the rest of the population. Then inevitably those who argue for "special" rights and needs must argue in a way that is quite distinct from how the issue would be addressed if the right were assumed. But if the assumption is instead that these needs and rights are not in fact special, then the discussion is about the best and most expedient way to change the systems so that they take disability, a rather unexceptional humanoccurrence, into account. It puts the individual with a disability in the same position as any other citizen to require that, if governments set up public programs or establish policies, such public policy must by definition consider disability.

The myriad of issues that disadvantage people with disabilities cannot be addressed in a piecemeal fashion as they interact with one another to provide cumulative barriers to social and economic integration and equality. It is our view that they can, however, interact in such a way that they provide cumulative solutions. The research studies that we have undertaken, of which this is one, aim to examine public policy in the area of disability from this perspective. As we address the issues from the disability framework outlined here, we believe we move closer to real solutions.

Poor Places fits into the overall series of policy studies being initiated and undertaken by The G. Allan Roeher Institute. It is a companion study to one recently undertaken by The Institute, *Income Insecurity: The Disability Income System in Canada*, which analyzed the programs of income support for persons with a disability. Other complementary studies that have been published by The Institute in recent months include, *The Power to Choose*, which examined a unique method of service delivery through service brokerage and individualized funding. *Literacy and Labels: A Look at Literacy Policy and People with Mental Handicaps*, another of The Institute's studies, examines the issue of literacy including conventional notions of literacy, as well as policy initiatives and program developments and the impact these have on creating opportunities for people with mental handicaps to be integrated in Canadian society. An ongoing study by The Institute on employment-related federal and provincial policy and programs (to be released in 1991) will provide further insight into economic and social involvement of persons with disabilities. The employment-related programs being examined include income programs, training programs,

regulatory programs, workplace modification programs and job creation programs.

Poor Places examines another system of services: disability-related housing and support services. The study describes the major sources of funds which support these services: The Canada Mortgage and Housing Corporation (CMHC), the Canada Assistance Plan (CAP), Established Programs Financing (EPF) and Extended Health Care Services (the CAP/EPF interface). It analyzes the problems that arise as a direct or indirect result of these funding arrangements.

The study proposes a variety of policy options for improving the availability and quality of disability-related housing and support services. In relation to housing, both the supply of affordable housing and assistance for the costs of housing are considered. Policy options include an expanded Rent Supplement Program, a shelter tax credit, more generous shelter allowances within welfare benefits and an enhanced Residential Rehabilitation Assistance Program for the Disabled.

The following options for improving support services are explored: the redirection of CAP/EPF interface funds, expanded use of CAP, changes to EPF funding, modifications to funding provided by CMHC, new cost-sharing arrangements, individualized funding and enhanced funding for family supports.

The study also considers funding sources for personal supports including personal support networks, brokerage and advocacy.

Finally, *Poor Places* strongly advocates the funding of only those organizations whose programs embody three fundamental principles of equality: inclusion, citizenship and self-determination.

I would like to thank many people for their assistance in this study. First, I would like to thank a number of people who acted as researchers and advisors on the project including Sherri Torjman, Cameron Crawford, Paula Dorval, Ken Battle, Diane Richler, Dale Falkenhagen, Dick Zuker, David Cruickshank, and Bob McLarty.

I would also like to thank the Disabled Persons Unit, Health and Welfare Canada for their financial support of the project.

The federal, provincial and territorial governments generously provided the bulk of the raw statistical information for this study and reviewed the data for accuracy prior to its publication. I would like to thank them for their cooperation in the study and hope that it will be useful to them.

This study, like all our work, is dedicated to persons with a

disability in Canada. It is my hope that this attempt to unravel and clarify the issues around disability-related housing and support services will be a step towards the achievement of full citizenship and equality for them.

Marcia H. Rioux
Director

Introduction

Most residences for individuals with a disability are places for poor people. Furthermore, most of these housing arrangements are very poor places.

Residences for persons with a disability may indeed be called "houses" in that they provide basic shelter. However, few are true homes that afford a sense of security and allow opportunities for decision making, personal growth, and development.

Many of the residences that will be discussed in this study have effectively removed individuals from the mainstream of the community. Some housing options have stripped residents of their citizenship in the broadest sense of the word.

These problems stem largely from the fact that the individuals for whom these housing arrangements have been set up are devalued people. Many were formerly housed in institutions where they were not viewed as worthwhile human beings.

Most of the residents are poor; the majority are welfare recipients whose benefits fall well below poverty levels.[1] The minority who work usually have a tenuous attachment to the labour market and generally earn the minimum wage. In short, the various housing arrangements that will be discussed in this study have become options for "warehousing" poor people.

The difficulties arising from poverty are compounded by the fact that these persons have a disability. Most incur higher costs as a result of their disabling condition. Many rely upon a range of support services to assist them with the activities of daily living. Yet, as this study will show, these services are also riddled with problems. One of the major weaknesses of the service system is that each of the various programs of which it is comprised has a unique set of eligibility criteria. Individuals must qualify on the basis of these criteria in order to receive the service. If, for some reason, their needs do not fit the requirements (e.g., the service may be intended for persons who have a particular physical condition or who are of a certain age), then the service is denied. The system is particularly ill-equipped to address the needs of persons with a multiple handicap such as blindness and mental handicap or deafness and psychiatric disability.

Individuals are turned away for other reasons as well. Sometimes there are not enough services. The demand simply outweighs the supply.

Yet another weakness of the service system is that programs are generally established to serve one-of-a-kind problems: income, housing, training, or attendant care. Services tend to deal only with the specific component of need they have been established to address.

Most services are organized as though individuals' lives are compartmentalized into neat categories. They are set up as though level and source of income have no relationship to housing needs; availability of attendant care has no links to a person's ability to participate in a life skills program; access to technical aids has no bearing upon participation in a vocational training program.

Problems also arise in relation to lack of choice. While a person may qualify for a service according to the eligibility criteria, it may not be particularly effective in meeting his or her needs (e.g., sheltered workshops rarely teach the skills required for real jobs). Yet there is nothing the participant can do because there is often no other service. He or she is considered lucky to have found a program at all. The only choice is no choice.

In short, the needs of many Canadians with a disability are not being adequately met or addressed at all. The purpose of this study is to explore the services — more specifically, the housing and support services — that are required by and provided to individuals with a disability to help them live and participate as full citizens.

Poor Places examines the sources of funding for these services and considers the implications of this financial structure. It also analyzes how current legislative and funding bases as well as delivery mechanisms often impede rather than support the provision of services. Finally, it presents policy options under existing and new cost-sharing arrangements.

This study should leave no doubt that the poor places that house persons with a disability are unacceptable. These housing arrangements require fundamental reform that must be effected through a shift both in philosophy and in funding.

Chapter 1:

The Focus of This Study

Poor Places is a follow-up to a study recently published by The G. Allan Roeher Institute entitled *Income Insecurity: The Disability Income System in Canada*. That study described the complex system of income security programs for persons with a disability. It analyzed the problems arising from the patchwork of programs that provide less than poverty line incomes.

Poor Places moves beyond a discussion of financial circumstances and examines the next layer of need: housing and support services. This layered approach to the exploration of needs and services has evolved on the basis of the conceptual framework described below.

All individuals have basic living needs that must be met in order to ensure well-being. These needs form a hierarchy; certain needs have to be satisfied before others can be addressed.[2] The satisfaction of physical requirements such as food, shelter, and clothing is a prerequisite to the satisfaction of other higher level needs such as socialization.

Needs can be conceptualized as a pyramid in which physical needs comprise the base and social and psychological needs form the top. If expanded and articulated in greater detail, the core concepts can be framed as a series of concentric circles (Figure 1). While all human needs are important, there is a relative hierarchy; the needs closest to the core must be satisfied before or at least at the same time as the needs in the outer rings.

These needs are generic in that they are common to all persons including those with any form of disability. In the latter case, however, certain individuals may have special needs arising from their disabling

Figure 1
Individual Needs

condition. These may include medications, communications-related equipment, attendant care, or life skills training. The conceptual framework presented in Figure 1 can be broadened by adding the necessary rings in the appropriate places (Figure 2).

The concentric circles in Figure 2 are not intended to imply that certain needs take priority over other needs for all individuals and at all times. For some persons, the need for disability-related equipment will be more important than their need for housing. They may live in a family home but they may have difficulty obtaining an expensive piece of communication-related equipment such as a teletypewriter (TTY). Some individuals do not need vocational training; however, their need for special transportation to get to a place of work may be of critical importance.

The concentric circles represent the fact that the hierarchy of needs follows a relatively similar pattern even though these may vary by individual. It also implies that each component has to be explored systematically in order to determine the barriers to community living and to identify where the appropriate interventions are required.

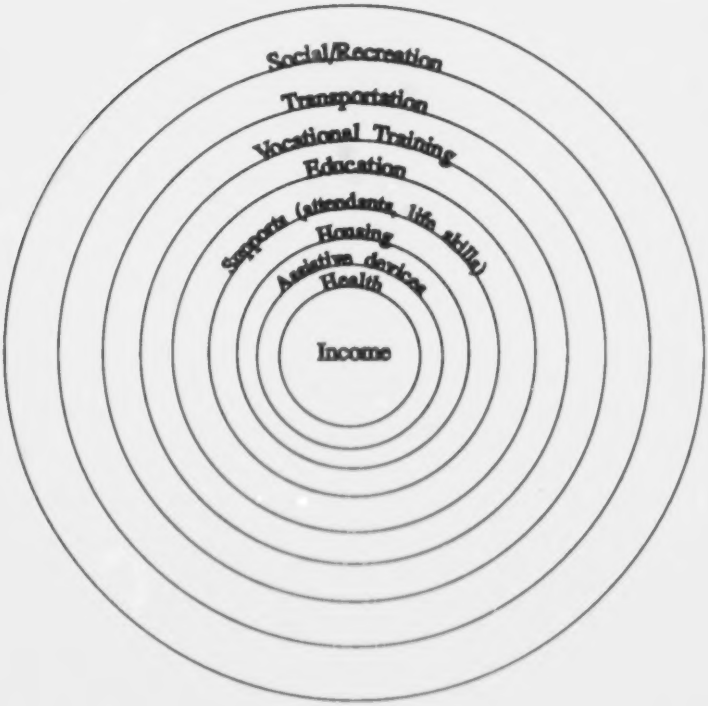
In short, this framework should not be seen as a static concept. Rather, it is a conceptual tool intended to help develop a methodical and comprehensive approach for studying the needs of and services for persons with a disability.

Income Insecurity was an in-depth exploration of the various programs and issues related to income security. *Poor Places* examines several of the other rings or components related to living in the community — more specifically, housing options and support services such as attendant care, life skills training and homemaker services.

Housing and support services were chosen as the next area of study because of their proximity to the core. They are absolutely fundamental to community living. Despite their critical importance, these services have been plagued by a variety of problems that impede their effective provision. Many of these problems arise as a result of the philosophical orientation of these services. Other problems are a direct result of the funding arrangements.

Chapter Two on Funding Arrangements presents some general concepts with respect to the funding of these services. It is followed by a discussion of the various sources of funds for disability- related housing and support services (Funding Sources). The possible combinations of housing and support services are presented in the form of a continuum of service delivery. The Analysis identifies the problems

Figure 2
Individual and Special Needs



with these arrangements and explores why change is required. Finally, the chapter on Policy Options points to possible directions for change.

Chapter 2:

Funding Arrangements

Before examining the disability-related housing and support services currently in place, it is instructive to explore some basic funding concepts. These concepts relate to funding auspices and to the methods of transferring funds from governments to individuals and to organizations.

FUNDING AUSPICES

Current funding arrangements have a major impact upon the availability and quality of services intended for persons with a disability. The source and level of funding can either enhance or impede the effective provision of services. While source and level of funds are critical factors, these must be understood within the context of funding auspices. There are three major types of funding auspices under which funds can flow to disability-related housing and support services: public auspices, private auspices, and a combination of both.

Services delivered under public auspices are supported by tax dollars. The funds may come from any level of government: federal, provincial, regional, municipal, or a combination of levels such as federal/provincial or federal/provincial/municipal. Social assistance (welfare) and insured health care services (medicare) are examples of publicly funded programs.

Services made available under private auspices are those whose funds flow from non-government sources such as voluntary organiza-

tions, service clubs, corporations, endowment funds, or foundations. Examples of privately funded services are social and recreational programs organized by a family service agency for a particular group of individuals or special transportation made available by some service clubs.

It is becoming more difficult to classify a service as either exclusively public or private. Services are now frequently supported through various combinations of public and private funds. Increasingly, governments are devolving the delivery of services provided in the public domain to the private sector. These quasi-public services operate in a variety of ways.

Generally, public funds are allocated to a private organization, such as a non-profit agency, to provide a certain service. For example, an association representing persons with a disability may receive a government grant to set up a vocational rehabilitation program. A family agency may bill the government on a case by case basis for counselling services.

Most disability-related housing and support services now fall within the quasi-public domain. They are delivered by private agencies with varying amounts, sources, and combinations of public funds. The type of funding auspice has important implications for the nature, quality, and extent of the service.

Services that are publicly funded tend to be relatively secure (although, at a time when most publicly funded social programs are being eroded, perhaps a more accurate characterization would be "less precarious" than other forms of funding). While publicly funded programs are often predicated upon a set of principles intended to ensure public access and coverage (e.g., medicare), their administration is usually insular and rarely accessible (or comprehensible). The decision-making processes under which many of the programs operate are unknown to the public and especially to the consumers of the service — the very persons for whom the service was intended.

Ironically, most public programs are governed by rules and policies that are rarely made known to the public, let alone formulated with public input. The only public aspect of these programs is the taxpayers' dollars that support them. There is a clear trade-off: relatively secure funding for services over which consumers and other community members have little control.

In the private arena, the trade-off is different but no less paradoxical. Privately funded services are often provided through

locally based organizations run by consumer boards.

These agencies have the potential for being open, flexible, and controlled by consumers. (However, many private organizations in fact serve only particular interests or have kept consumers off their boards.) In theory, private organizations are essentially tied only by their own hands; they can be creative and adaptable. They can provide services in response to emerging needs. They can try innovative methods of delivery. They can afford to be on the leading edge of service provision.

The problem is that being creative is just about the only thing that most private organizations can afford. Many operate on a shoestring budget. They must depend on funding bodies such as the United Way, and on various sources such as memberships, donations, bake sales, and craft fairs. Compounding the tight budget problem is the fact that many organizations do not or would not want to charge a fee for their services as these generally assist low-income individuals and families.

Another weakness with the private provision of services is that these are not necessarily made available on an equitable basis or to all those in need. For example, a board of directors could decide that an agency will serve only those with a particular illness (e.g., multiple sclerosis). Many organizations are, in fact, set up around specific conditions and direct their attention only or primarily to persons with that condition.

While the individuals and families directly involved are the lifeblood of these organizations, there are inequities in the private provision of services. If two persons in a given community require special transportation, only one may actually receive the service because he or she has a particular condition that is served by the organization, while the other has no similar entitlement. The unfortunate individual with a multiple handicap, such as blindness and a mental handicap or a hearing impairment and psychiatric disability, usually gets lost in the buck-passing that goes on between agencies.

The narrow focus of private agencies is understandable given their limited resources and the fact that most operate on volunteer (borrowed, when available) time. The organization can accomplish only as much as the individuals who constitute its board of directors are reasonably able to contribute.

A problem that goes deeper than the agency selection of a narrow or manageable target is the fact that focused delivery can be construed

as discriminatory. For example, an organization may decide to help individuals of a particular religious, linguistic or ethnic background only. This is a different type of selectivity than representing one type of disability or assisting people with a specific condition.

Another difficulty arising in relation to private auspices is the possibility that the services are being provided by an organization that may be relatively unstable in terms of funding, directorship, or staffing. Yet these services may be essential (e.g., attendant care) to the well-being, and in some cases, survival of persons with a disability. In many instances, the importance of the services is not matched by the stability of the organization(s) responsible for their provision.

In theory at least, the quasi-public arrangement combines the best of both worlds: locally determined, community-based decision making supported by a relatively stable source of (public) funding. Yet, somehow, the best of both worlds combination has not worked out in the real world. There are several problems relating to conditions of eligibility, lack of portability, lack of coordination, and private administration.

While the funds derived from public sources are relatively stable, these dollars are tied to legislation and policies that require services to be delivered in a certain way (e.g., the Canada Assistance Plan stipulates that funds for welfare services be directed to public or non-profit agencies); for a designated period of time (e.g., short-term intervention); or to particular populations (e.g., to individuals with "high employment potential," "in need" or below specified income levels). In other words, the funds can go only to programs or services that meet, first and foremost, the funding criteria. The second priority is how effectively they are able to respond to individuals' needs.

The fact that funding for the given service may flow from different pots of money within the same government department, from different departments at the same level, and/or from different levels of government can create an almost exhausting labyrinth for the organization trying to deliver community-based services. Unfortunately, it is not only the sponsoring organization that experiences difficulty in relation to the current funding arrangements.

The person who requires assistance is often left trying to put together the pieces of an intricate puzzle. If only one piece is missing, the puzzle is incomplete. A missing component can be disastrous, often leaving an individual unable to function independently.

Lack of coordination stems from the fact that disability-related

housing and support services are funded and delivered under a variety of sources and auspices creating a veritable patchwork arrangement. One way of overcoming this patchwork effect is to centralize the funding source — i.e., to pool all the dollars intended for services for persons with a disability and provide these through one department. While this may be an administratively easy answer, it creates other kinds of problems. Most important, it has the effect of "ghettoizing" individuals with a disability.

Another problem arises in relation to portability. Funds are tied to certain structures (e.g., institutions, non-profit organizations). In order to receive services, individuals become locked in to the service organizations. If a person moves to a different community or if his or her needs change (he or she requires less support, more assistance, or another form of support), the process of putting the puzzle together has to begin all over again. The program or service remains; it is the person who must move, change, or adapt.

Finally, it was previously indicated that most programs for persons with a disability are provided under quasi-public auspices: delivered by private agencies with the support of public funds. While private administration has its advantages, it can also give rise to serious problems. It can result in great inequities in service provision, not only throughout the country and within the same province but also within a small geographic area where a given agency may serve only a particular neighbourhood or "type" of individual.

These and related problems are described more fully in Chapter Five.

METHODS OF TRANSFERRING FUNDS

Governments distribute funds to individuals, programs, and services through transfers, taxes, or a combination of taxes and transfers.

Transfers

"Transfers" refer to a sum of money that one level of government provides to another level of government or provides directly to individuals. There are several types of transfers. Unconditional transfers, for example, are the amounts of money that the federal government

must provide to the provinces and territories as a result of various agreements. Unconditional transfers include equalization payments, grants in lieu of taxes, and established programs financing. The latter is the funding mechanism that supports the national health care system (described in the next chapter). Transfers are also made by governments to individuals in the form of flat-rate payments or demogrants. Examples include the monthly family allowance and Old Age Security benefit paid by the federal government to families with children and to individuals over the age of sixty-five, respectively. It should be noted that, because these demogrants (flat-rate amounts) are taxable, their actual value varies by level of income. The tax system effectively ensures that benefits are distributed according to financial need.

Government transfers are also made to individuals on an income-tested basis. That is, eligibility for these transfers is determined according to level of income. Examples include the federal refundable Child Tax Credit provided to low- and middle-income families and the Guaranteed Income Supplement for low-income seniors.

Student loans, training allowances, and mobility grants are other types of transfers that governments provide to individuals on the basis of established criteria.

In addition to transfers that higher levels of government make to lower levels of government or that governments make to individuals, there are some transfers that require a contribution by another level of government. These are referred to as cost-shared programs. For example, under the Canada Assistance Plan (discussed in the next chapter), the federal government shares with the provincial and territorial governments 50 percent of the costs of financial assistance and services for persons "in need."

Taxes

The tax system is not generally regarded as a means of distributing income or redistributing funds from one source to another. Rather, it is most commonly viewed as a means of taking money away! However, the tax system is an important mechanism for redistributing income. It does so through tax exemptions, deductions, and credits.

Exemptions and deductions provide income tax savings that rise with income. They act to lower the amount of income on which individu-

als are required to pay tax. Because they are taxed at a higher top tax rate, taxpayers with higher incomes benefit more from an exemption or deduction than lower-income taxpayers.

Tax credits, by contrast, are deducted from tax payable. Because credits are taken off after tax payable is calculated, they generally provide equal tax savings to all taxpayers. However, credits are worth more in relative terms to persons with low incomes. For example, a $1,000 tax credit would amount to 10 percent of the income of a tax filer with an income of $10,000, but only two percent of the income of someone with an income of $50,000.

There are several income tax provisions that are of particular importance to individuals with a disability: the personal credit, the disability credit, and the medical expenses credit. The *Income Insecurity* study identified their weaknesses — including the non-refundability of the credits (they do not help persons too poor to pay tax), the limitations of the definitions currently employed to qualify for the disability and medical expenses credits, the elimination of the employment expenses deduction, and the lack of provision for the costs of workplace modifications.

It should be noted that a tax deduction to help workers certified as having a severe and prolonged impairment has recently been introduced. These workers will be allowed to deduct from their taxable income the costs of care provided by a part-time attendant who is an unrelated adult.

The next chapter on Funding Sources describes the federal sources of funds for disability-related housing and support services. The primary focus is upon transfers: the monies that the federal government provides for these services under various funding arrangements. The tax system will be considered again in the final chapter on Policy Options.

Chapter 3:

Funding Sources

There are several federal sources that currently provide funds for disability-related housing and support services. These include the Canada Mortgage and Housing Corporation, the Canada Assistance Plan, Established Programs Financing, and Extended Health Care Services. Each of these funding sources is described more fully below.

Costs are shared with provincial and territorial governments that, in turn, deliver services directly or purchase services from municipal governments or from private (usually non-profit) organizations. The various combinations of funds employed for different service models are described in Chapter Four.

CANADA MORTGAGE AND HOUSING CORPORATION

The central agency responsible for national housing policy is the Canada Mortgage and Housing Corporation (CMHC). The National Housing Act sets out CMHC's mission: to promote the construction of new housing, the repair and modernization of existing residences, and the improvement of housing and living conditions.

In carrying out this mandate, the Corporation makes available loans, grants, and subsidies for the development of housing. It also provides mortgage loan insurance — that is, it protects lenders against any losses they may incur if borrowers, such as non-profit agencies that run community-based residences, cannot meet their monthly mortgage payments.

While CMHC is involved in a wide range of activities with respect to the housing market, there are four programs in particular that assist individuals with a disability. Under the Residential Rehabilitation Assistance Program for the Disabled, funds are made available for improving the quality and accessibility of housing. A second major program is the Rent Supplement Program that allows the Corporation to share the costs of subsidies to offset high rents. Finally, CMHC contributes to the supply of housing through its social housing program, which consists of two components: the Non-Profit Housing Program and the Cooperative Housing Program (although technically, the latter is considered to be a market housing program because of the income ranges of the occupants). These four programs are described more fully below.

The delivery of housing programs has devolved to the provinces in all jurisdictions except Prince Edward Island and the Northwest Territories. This means that individuals and organizations must approach provincial/territorial governments (or a designated body such as a municipal corporation) for assistance. Each province/territory has, in turn, entered into an agreement with the federal government. The agreement identifies the respective financial contribution to the specific programs that each government is expected to make and outlines the parameters for delivery, administration, and financial control.

Residential Rehabilitation Assistance Program (RRAP)

The purpose of the RRAP for the Disabled is to help offset the costs of improving the accessibility of existing housing. The assistance is provided to homeowners with a disability or to families that have a member with a disability. It can also be made available to a landlord who would like to make a particular unit accessible. Special care housing, nursing homes, and hospitals are not eligible for these funds.

The contribution is not paid as an outright grant but as a forgivable loan over a fifteen-year period. The monies can be used to cover any costs required for improving accessibility including materials, labour, financing, building plans, and permits. While the contribution does not have to be repaid, the fact that the funds are given out over an extended period of time ensures that CMHC retains some control over the way these are used.

Funds are available under this program in all provinces and

territories except Newfoundland, New Brunswick, and Quebec, which operate analogous programs. The latter provinces share program costs with the federal government. In the rest of the country, the federal government pays the entire cost of the program.

It is also important to note that recent changes to the tax system will provide modest assistance to individuals who have repaired their homes for the purpose of improving physical accessibility. The associated costs may now be claimed as an eligible medical expense under the medical expenses credit. However, this credit is not refundable and therefore provides no assistance to persons who are too poor to pay tax.

Rent Supplement Program

The purpose of the Rent Supplement Program is to help low-income individuals and families obtain suitable rental housing by subsidizing the rents in designated rental or cooperative accommodation. Households are eligible for rent supplementation if they have to pay more than 30 percent of their incomes for suitable accommodation on the market.

Under this program, the province or territory enters into an agreement, either directly or through a local housing authority, with a private landlord to set aside a designated number of units for low-income persons. The program helps households in need by placing a limit on the amount of their income that is used for rent. There are both federal and provincial rent-to-income scales employed to determine the maximum amounts of rent by income level. Some jurisdictions use their own scale while others use the federal scale. CMHC, however, will not share in any costs beyond the limits of the federal scale.

Units are then leased by the province/territory or its designated agency for a period of up to thirty-five years. The lease identifies the cost of the unit that is equivalent to the market rent: the amount that such a unit would cost on the open market in a comparable neighbourhood dwelling. The market rent is generally greater than the geared-to-income rent. Under Federal-Provincial Operating Agreements, the federal and provincial/territorial governments provide a subsidy by sharing the cost of the difference between the rent-geared-to-income revenue and the market rent.

There is also an economic rent: the term used to designate the monthly cost of the dwelling that must be paid by the landlord

including mortgage payments, utilities, taxes, and insurance. If the economic rent is greater than the market rent, the landlord must come up with the difference.

Table 1 presents a summary of the cost-sharing agreements for the rent supplement by province and territory. The first figure indicates the federal portion; the second is the provincial/territorial contribution. While the agreements vary by province and territory, it can be seen that the federal government pays the greater share in all jurisdictions except in Prince Edward Island where the federal government pays 100 percent of the costs.

Non-Profit Housing Program

Most of the voluntary (private) organizations requiring financial assistance for supported residences seek assistance through the Non-Profit Housing Program. Provincial/territorial bodies, municipalities, and municipally designated agencies are also eligible for funding under this stream. The major requirement is that the sponsor must be a "bona fide" non-profit organization.

Provinces and territories are responsible for selecting the projects that will receive this form of funding. Every year, they place announcements inviting applications for non-profit housing projects. The applications are screened according to a set of criteria that include the merit of the project, the extent of need, the "soundness" of the group applying, and the cost-effectiveness of the proposal. The eligible capital costs of projects must be within maximum unit prices that are established by the two levels of government.

The province or territory then selects a certain number of these to move into the "developmental phase": the period of time during which they are expected to develop their plans more fully. A developmental contribution of up to $75,000 may be made available to help the group formulate its plans; a regulatory amendment has been approved that will increase this amount to $500,000. These funds are intended to cover the initial planning and development costs associated with preparing a proposal.

If the project is accepted and committed, the $75,000 is rolled into the mortgage and repayment of the development loan is subsidized by government. If the project is refused, the loan may be forgiven (it does not have to be repaid).

Table 1
Rent Supplement Program
Cost-Sharing Arrangements, 1989

	Federal contribution %	Provincial contribution %
Newfoundland	75	25
Prince Edward Island	100	--
Nova Scotia	75	25
New Brunswick	75	25
Quebec[1]	62	38
Ontario	60	40
Manitoba	75	25
Saskatchewan	75	25
Alberta	70	30
British Columbia	67	33
Northwest Territories	75	25
Yukon	75	25

[1]The federal/provincial sharing for cooperatives is 75/25, respectively.

Source: Canada Mortgage and Housing Corporation

An organization working on behalf of persons with special needs may be exempted by the province or territory from this competitive selection process. An agency representing a particular set of interests may receive developmental funds if the province determines that there is a need in a given community for housing for a certain population such as individuals with a mental handicap or persons with a spinal cord injury.

When the developmental process is complete, the project must be approved by the provincial/territorial housing authority. If approval is received, the non-profit sponsor must approach a private lender, such as a bank or trust company, in order to obtain a loan to cover the costs of building or renovation.

CMHC acts as the guarantor of this loan through its Mortgage Insurance Fund. In other words, if for some reason the non-profit organization experiences serious financial difficulties and can no longer meet the monthly payments, CMHC assumes responsibility for the outstanding amount of the loan. Without this back-up security, no private lender would bear the risk of lending money to a non-profit organization for a costly undertaking such as a housing project.

Once the project proposal is approved and a commitment is made to insure the loan and provide ongoing assistance, money is advanced from the private lender to the sponsor to begin construction or renovation. When the residence is complete and actually ready for occupancy, the non-profit sponsor must begin to repay the loan at a point in time called the "interest adjustment date." The repayments include mortgage costs and may incorporate other costs as well, such as taxes, utilities, insurance, and administration. These payments constitute the economic rent.

Despite the fact that these are non-profit housing arrangements, the sponsor nevertheless derives revenue from the monthly amounts paid by residents. To be eligible for this form of housing, a household has to be paying more than 30 percent of its income for adequate and suitable housing. Household income must fall below certain threshold levels that are established by market area. "Adequate" refers to structural features, indoor plumbing, proper heating and ventilation, and other physical features. "Suitable" refers to overcrowding; this criterion is intended to ensure that families are not living in overcrowded conditions.

The rents paid in the residences funded under this program should not exceed 30 percent of income (i.e., for the units for which the

federal government shares the costs). The economic rent — that is, eligible operational costs including the monthly amount that the non-profit organization must repay to the private lender — is generally greater than the amount of revenue derived from the rent-geared-to-income rental payments. The difference between the economic rent and the revenue is cost-shared by the federal and provincial governments (and by Yukon) on a monthly basis for the duration of the mortgage, which is generally repaid over a period of thirty-five years.

The respective contributions of the federal and provincial governments (as well as Yukon) are outlined in Table 2. Some provinces, such as Ontario, provide subsidies for households in addition to those shared with the federal government. These extra subsidies are fully funded by the provinces.

The first number in Table 2 represents the percentage of federal contribution while the second indicates the provincial portion. The designation "prov," "terr," or "CMHC" refers to the level of government responsible for the day-to-day program operations. The table shows that, in most cases, the federal-provincial cost-sharing split is 75/25 (although it is 62/38 in Quebec, 60/40 in Ontario, and 70/30 in Alberta).

Table 2 makes clear the fact that the provinces are the primary delivery parties except in Prince Edward Island and the Northwest Territories where the federal government pays 100 percent of the costs. This means that community groups setting up residences for persons with a disability must deal primarily with a provincial housing authority.

The payment of the difference between the economic rent and the rent-geared-to-income revenue represents a relatively new method of subsidizing non-profit housing projects. A different funding mechanism was formerly in place in which the federal and provincial governments helped write down the mortgage to 2 percent by subsidizing the difference between the actual interest rate (e.g.,12 percent) and the 2 percent level. This subsidy is cost-shared in varying proportions by both levels of government.

While this form of financing is being phased out over the next five years, CMHC will nevertheless be locked into this arrangement for a substantial period of time. Many projects are supported under a thirty-five-year mortgage.

The number of special purpose projects eligible for assistance under this program cannot exceed 10 percent of the province's budget for social housing units. That is, only 10 percent of all social housing

Table 2
Non-Profit Housing
Cost-Sharing Arrangements, 1989

	Federal contribution %	Provincial contribution %	
Newfoundland	75	25	prov.
Prince Edward Island	100	--	CMHC
Nova Scotia	75	25	prov.
New Brunswick	75	25	prov.
Quebec[1]	62	38	prov.
Ontario	60	40	prov.
Manitoba	75	25	prov.
Saskatchewan	75	25	prov.
Alberta	70	30	prov.
British Columbia	67	33	prov.
Northwest Territories	100	-	CMHC
Yukon	75	25	terr.

[1]The formula indicated is for publicly-sponsored housing programs. The federal/provincial cost-sharing arrangement for private sponsors is 75/25 per cent, respectively.

Source: Canada Mortgage and Housing Corporation

projects in any given province can benefit from this interest rate assistance. The new funding arrangement is, in fact, more beneficial to low-income households because it guarantees that the rent they pay will not exceed a certain percentage of their income. By subsidizing the difference between the economic rent and the rent-geared-to-income revenue, rents are kept at low levels and the project accomplishes more effectively its intended purpose (assisting low-income households).

Of great interest to persons with a disability is the fact that CMHC encourages all projects that receive funding under the Non-Profit Housing Program to ensure that at least 5 percent of units are mobility units in which space is allowed for manouvering a wheelchair. Switches and controls are positioned at wheelchair level. While the unit is designed for the installation of special cabinets and grab bars, these features are not actually provided.

If, however, the project is to be designed as or to include a fully accessible facility free of architectural barriers outlined in the design standards of the National Building Code, then extra funds will be provided to assist with the costs. The maximum unit price for building, which is set for each major market area, may be increased by up to 12 percent to render the unit or project fully accessible.

An important development with respect to social housing is worth noting. The federal and provincial governments have been negotiating the development of non-profit projects designated for persons with special needs. The federal government wants to ensure that housing dollars are allocated only for the shelter component of the project and not for any of the costs incurred in providing special care for the residents.

For example, a workshop or therapeutic area is sometimes argued to be necessary within a residence for life skills training or social/recreational activity. Space used in this way would not qualify as a residential cost; it is considered to be a cost associated with the provision of care. CMHC has determined that this is not to be included in the calculation of eligible economic rent. The costs arising from the square footage of "support service/care" space would have to be borne directly by the non-profit sponsor.

Subject to a loan insurance agreement between Canada and the provinces/territories, the capital costs of non-eligible space can be included in the insured loan amount. The repayment of this portion of the loan and associated operating costs for this space will not be subsidized by CMHC. In the case of default, the province or territory is

totally responsible for this cost. This means that the organization has to seek a private source of funds such as an individual donor, corporation, or service club unless funds for this purpose are provided by another level of government (e.g., provincial department of social services).

Cooperative Housing Program

The purpose of the federal Cooperative Housing Program is to support the development of cooperative housing for moderate-income households that cannot afford to own a home. Cooperatives are incorporated associations that provide housing for their members. The members do not own the housing. It remains the property of the association. Because the housing is owned and managed by a cooperative, this type of residential project is in a position to control its operating costs.

The Cooperative Housing Program makes provision for the building of new houses, the purchase or repair of existing housing or the conversion of non-residential buildings into dwellings. Cost limits are imposed by CMHC to ensure that these remain modest. The maximum unit prices are the same as those under the Non-Profit Housing Program.

Organizations wishing to set up a cooperative housing project are eligible for up to $500,000 of developmental funding. These funds are repayable as part of the mortgage cost if the project is accepted.

In contrast to the Non-Profit Housing Program in which provinces generally select the housing projects to be funded, CMHC is responsible for the selection and funding of eligible projects under the Cooperative Housing Program. CMHC will provide insurance on the mortgage financing for 100 percent of the approved costs. Again, this insurance covers only the costs related to the shelter component of the project and not to any space designated for care or service.

Cooperatives are financed through a mechanism called the "index-linked mortgage." This type of mortgage arrangement involves the removal of the inflationary factor in calculating mortgage rent. Up to 100 percent of capital costs for eligible cooperatives may be financed through a CMHC-insured index-linked mortgage from a private lender with a repayment period of thirty years.

An index-linked mortgage is one in which the initial mortgage payments are kept relatively low. The payments then increase year by

year by 2 percent less than the rate of inflation. This means that the amount of the mortgage rent increase is always lower than the increase in the cost of living. If the mortgage payments and other operating costs in the first year of operation require charges in excess of market rents, federal assistance is provided to reduce the charges to market levels.

The process works in the following way. In the first year of operation, the economic rent is calculated. This consists of the monthly payments for the index-linked mortgage and other operating costs such as taxes, utilities, and insurance. Say, for example, that this economic rent amounts to $1,000 a month. A market rent is then identified by determining the monthly rental costs of comparable accommodation in the private market — say $800. CMHC will subsidize the difference between the economic rent and the market rent — in this case, $200.

In the second and subsequent years, CMHC provides a subsidy equivalent to $200 a month (the base year subsidy) plus the same inflationary factor that applies to the index-linked mortgage. Cooperatives that are efficient in their operations can reduce their operating costs in areas such as maintenance and come out ahead in this funding process. Those that are not functioning as efficiently will likely have to raise the rents (called "occupancy charges" in a cooperative housing arrangement).

In addition to support of the housing project, CMHC has agreements with provinces to extend the Rent Supplement Program to cooperatives. Half of the provinces provide the supplement for 50 percent of units in projects assisted under the Cooperative Housing Program; the remaining provinces extend the supplement to 30 percent of the units in a given project. Cooperatives assisted under this program must also designate at least 5 percent of their units for persons with a physical disability.

Table 3 indicates the actual amounts that CMHC spent on social housing programs in each province and territory in 1987-88 and 1988-89. These expenditures do not include amounts for cooperative housing; these are included in CMHC's calculations for "market housing."

In short, CMHC in conjunction with its provincial and territorial counterparts, provides assistance with rental costs and funds for the physical premises of selected non-profit or cooperative housing projects. The funding for residential care such as room and board, support services, and health-related services — i.e., costs related to the operational component of the housing — are funded under different mechanisms: the Canada Assistance Plan, Established Programs Financing,

Table 3
Federal Social Housing Expenditure by Province/Territory (thousands of dollars)

	1987/88	1988/89
Newfoundland	45 747	47 244
Prince Edward Island	6 895	7 974
Nova Scotia	50 000	57 120
New Brunswick	38 712	41 454
Quebec	227 062	240 374
Ontario	445 427	475 297
Manitoba	62 066	67 123
Saskatchewan	92 392	108 446
Alberta	94 611	100 973
British Columbia	174 555	163 822
Northwest Territories	50 960	61 723
Yukon	2 792	1 651
TOTAL	1 291 219	1 373 201

Source: Canada Mortgage and Housing Corporation

and Extended Health Care Services.

It should be noted that the February 1990 federal budget announced that funding for new commitments for social housing will be limited to $90 million in 1990-1991 and $86 million in 1991-1992, representing a cut to CMHC's social housing program.

CANADA ASSISTANCE PLAN

The Canada Assistance Plan (CAP) is the primary mechanism for financing social assistance and a wide variety of social services. CAP is administered by the Department of Health and Welfare. The Canada Assistance Plan Act of 1966 consolidated and expanded previous federal/provincial cost-sharing arrangements. The Act allows the federal government to pay up to 50 percent of the costs of social assistance and of certain services to persons in need or likely to be in need. (The February 1990 budget imposed a two-year limit on federal sharing to the provinces of Ontario, Alberta, and British Columbia to a 5 percent rise.)

Under Part I of the Act, there are two major funding streams: the assistance provisions and the welfare services provisions. Under the former provisions, provinces and municipalities can make available social assistance (or welfare) to persons in need for basic requirements such as food, clothing, shelter, utilities, household supplies, and personal requirements. The costs of special needs items and services, such as health-related equipment or devices required for work, may also be shared under the assistance provisions of CAP.

Assistance Provisions

In order to be considered eligible for social assistance or a special needs item or service, individuals and families must qualify on the basis of a needs test. That is, their needs must exceed the resources available to them through employment-related income, public or private pensions, or other sources. In addition, they must have liquid and fixed assets that fall below designated levels.

Financial assistance takes the form of direct payments to persons in need. In the case of special needs, assistance may be provided as a particular good such as a set of eyeglasses or a service such as

homemaker services.

Receipt of these special items is not necessarily guaranteed but is conditional upon a number of factors. It depends upon whether a province actually provides the particular good as a special needs item. Most jurisdictions consider essential health-related equipment as among the special needs they will fund. Assistance for other items that support community living, such as moving costs, a security deposit for an apartment, a telephone, or transportation, is not available in all provinces.

Individuals must qualify for special needs items on the basis of a needs test (i.e., they must have the budget deficit earlier described). Their need must also be approved by a caseworker or other designated person such as a physician. In other words, special needs items are made available on a discretionary basis. This has important implications for individuals with a disability who, more often than not, require extra assistance as a result of their disabling condition.

In addition to a welfare cheque or special item such as medication or equipment, provinces and territories may provide services to persons in need. These services are referred to as "prescribed services" in the CAP Regulation and include rehabilitation services, day care, homemaker services, and counselling. Individuals must also qualify for services on the basis of need.

The services authorized under the assistance provisions of CAP (rehabilitation services, day care, homemaker services, and counselling) may be provided by any type of agency. There is no legislative requirement that the agency be a non-profit or licensed organization. The services are purchased on an individual basis and only by a provincially approved agency, which cannot be a commercial agency. A federal contribution to these services is made only if individuals qualify on the basis of a needs test.

Furthermore, there is no limit to the amount that the federal government will share for the costs of welfare and for prescribed services under the assistance provisions of CAP (with the exception of the restriction imposed by the 1990 federal budget). Under these provisions, the amount paid for the service by the provincial or municipal government to or on behalf of the individual in need is a shareable cost.

The assistance provisions of CAP also allow for the cost-sharing of health care services and the care provided in a variety of residential facilities (called "homes for special care" in the CAP Act). These two types of services used to be funded like other CAP services on a 50-50

federal/provincial basis. However, the funding of health care services and the care provided in adult residential facilities has been substantially modified since the introduction of enabling legislation for insured health care services (described below under Established Programs Financing) and extended health care services (described under Extended Health Care Services).

Welfare Services Provisions

Cost-sharing is also provided for under the welfare services provisions of CAP. Section 2 of the Canada Assistance Plan defines "welfare services" as "having as their object the lessening, removal or prevention of the causes and effects of poverty, child neglect or dependence on public assistance." Welfare services include but are not limited to:

- rehabilitation services
- casework, counselling, assessment, and referral services
- adoption services
- homemaker, day care, and similar services
- community development services
- consulting, research, and evaluation services with respect to welfare programs
- administrative, secretarial, and clerical services, including staff training relating to the provision of any of the above services or to the provision of assistance.

Welfare services do not include services related primarily to education, corrections, health care (with the exceptions to be described below under Established Programs Financing and Extended Health Care Services), recreation, cultural activities, school social services, hospital social services, mental health services, and court-related services.

Under the welfare services provisions, federal contributions are made toward agency costs rather than toward the costs incurred by individuals or families as under the assistance provisions. Another significant difference between the assistance provisions and the welfare services provisions is that the latter allow cost-sharing for services directed toward individuals in need or those "likely to be in need" if they do not receive the service. The rationale for the "likely to be in need" component is preventive: to allow the delivery of services to individuals who may not be recipients of social assistance but who may be in

danger of slipping into poverty or experiencing serious problems if these services are not made available to them.

Individuals are generally considered "likely to be in need" on the basis of their levels of income (described below). It is important to note, however, the initiative arising out of the Federal/ Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities. The federal and provincial governments agreed to change the likelihood of need guideline. Adults with a disability who receive services targeted specifically to them can be considered persons whose income would be accepted within the existing guideline. The implications of this initiative are discussed in the chapter on Policy Options. It may be some time before the initiative changes current practices in certain jurisdictions that employ income levels to determine likelihood of need.

In general, the federal government sets guidelines for the net income levels for qualification on the basis of likelihood of need. A household with a net income below a designated "turning point" is eligible for a full subsidy (i.e., pays no fee for the service). In the final quarter of 1989 (October - December), the turning point was $13,668 for a single person, $27,336 for a single-parent family with one child (or a two-person family) and $36,456 for a two-parent family with two children.

Households with net incomes above the turning point pay part of the cost of the service until the "break-even" level: the point at which the subsidy ends. As of October-December 1989, the break-even level was $20,508 for a single person, $41,004 for a single-parent family with one child (or a two-person family), and $54,684 for a two-parent family with two children.

Provinces and territories set their own turning points and break-even levels for the income tests they administer to determine eligibility for services. Table 4 indicates the turning points and break-even levels that provinces and territories employ in the determination of eligibility for homemaker services and attendant care. Data in the table are presented for three household configurations: a single person, a single-parent family with one child, and a two-parent family with two children.

Yet another major difference in the funding provisions is the fact that services are eligible for cost-sharing under the welfare services stream only if they are provided by a provincially approved agency. CAP defines such an agency as a government department, a person, or an organization, such as a private, non-profit agency authorized by

Table 4
Eligibility for Homemaker and Attendant Care Services
Turning Points and Break-Even Levels[1]
October 1989

	Single person	Single-parent, one child	Two-parent, two children
Newfoundland	Each case is tested using an enriched needs test and service is provided accordingly.		
Prince Edward Island	$14,399 $33,600	$16,799 $36,000	$21,599 $40,800
Nova Scotia	$13,092 $13,092	$26,184 $26,184	$34,920 $34,920
New Brunswick	$13,668 $27,336	$36,456 --	-- --
Quebec	Services are provided on the basis of need determined by social services for a minimum contribution and then on the basis of special needs by *l'Office des personnes handicapées du Quebec*. There is no needs or income test: services are accessible on a universal basis to all persons who are disabled without consideration of their income.		
Ontario	Homemaker services are provided by municipalities and Indian bands. Individuals who are not welfare recipients undergo a needs test similar to the one used for general welfare assistance. Attendant care is provided through the Outreach Attendant Care Program and the Support Service Living Unit Program, neither of which requires an income test for qualification.		
Manitoba	These services are universal. Cost-sharing is obtained for welfare recipients and recipients of the Guaranteed Income Supplement for seniors; there is no needs or income test for these persons.		

continued on next page

Table 4
Eligibility for Homemaker and Attendant Care Services
Turning Points and Break-Even Levels[1]
October 1989

continued from previous page

	Single person	Single-parent, one child	Two-parent, two children
Saskatchewan[2]	$9,540 $16,740	$14,460 $21,660	$21,660 $28,860
Alberta	Use of income tests is no longer considered necessary as a result of the Federal/Provincial Review of Fiscal Arrangements Affecting Persons With Disabilities. It was agreed that persons with disabilties would be recognized as a "community of need".		
British Columbia	Unable to provide information.		
Northwest Territories	There is no particular income limit. Cases are assessed on the basis of financial need and individual situation.		
Yukon	Homemaker services are provided on a universal basis. There is no attendant care program.		

[1]The first figure represents the turning point while the second is the break-even level.

[2]In Saskatchewan, there is limited attendant care provided through a variety of agencies. The income levels indicated here apply to persons receiving attendant care through the provincial home care program.

provincial law or by a provincially designated authority to provide the services. Commercial agencies are not included in this definition. In other words, the service must be provided directly by a province, municipality, or voluntary organization.

Finally, under the welfare services provisions, the federal government will reimburse the provinces and territories for certain costs including salaries, benefits, and travel. CAP will not share in operating costs such as heat, light, telephone, rent, or insurance. Nor will it share in capital costs with the exception of day care and some computer costs. The lack of support for capital expenditure is an important limitation. It means that an organization setting up a new service or moving its operations to a different location for purposes of upgrading or easier access has to raise the money from provincial government sources or from private contributions.

Table 5 presents a summary of CAP expenditures for the fiscal year ending 1989. The implications of CAP funding are discussed in Chapter Five.

Even though the federal government contributes a substantial portion of the funding for disability-related services, these are administered and delivered at the provincial and territorial level. Provinces and territories may actually provide services directly or may purchase them from a municipal government or a municipal organization, such as a housing authority or a non-profit community-based agency. They may also be purchased from commercial agencies although the welfare services provisions of CAP preclude the cost-sharing of services delivered under private, for-profit auspices.

Support services are funded mainly through provincial departments of social services. The name of the department primarily responsible for the funding of these services in various provinces and territories is outlined in Table 6. Provincial departments of health are also involved in the funding of support services especially when these are provided in certain types of residential care facilities (described below) or when support services fall within the mental health field.

It should be noted that, in the provinces of Nova Scotia, Ontario, and Manitoba that have "two-tier" welfare systems, municipal governments play a major role in the delivery of welfare services. This means that they may provide the services themselves or may purchase them from a non-profit agency. Costs are shared with the provincial and federal governments.

Table 5
Federal Transfers ($000), Canada Assistance Plan, 1988-89[1]

	General assistance	Homes for special care	Health care	Child welfare	Welfare services	Work activity	Total
Nfld.	54 626	6 366	8 233	6 572	15 532	10	91 339
P. E. I.	12 455	2 589	997	795	5 766	-	22 602
N.S.	102 453	12 588	6 086	4 880	25 754	1 108	152 869
N.B.	113 768	5 717	6 148	3 212	20 944	-	149 789
Que.	724 117	154 196	53 328	18 001	179 331	-	1 128 973
Ont.	1 062 194	54 252	43 783	72 091	277 441	1 191	1 510 952
Man.	109 561	14 710	6 812	13 203	51 409	2 082	197 777
Sask.	100 067	12 484	1 521	4 892	36 037	152	155 153
Alta.	327 863	34 322	27 207	18 432	79 684	362	487 870
B.C.	439 187	55 377	33 257	4 329	130 962	-	663 112
NWT	7 189	1 995	0	1 532	4 336	-	15 003
Yukon	3 036	966	0	597	3 512	-	8 111

[1]While these amounts represent payments made in that year, they do not necessarily represent services provided in that year because of retroactive adjustments.
Source: Health and Welfare Canada

Table 6
Provincial/Territorial Departments Primarily Responsible for Support Services

Newfoundland	Department of Social Services
Prince Edward Island	Department of Health and Social Services
Nova Scotia	Department of Community Services
New Brunswick	Department of Income Assistance; Department of Health and Community Services
Quebec	*Ministère de la Santé et des Services sociaux*
Ontario	Ministry of Community and Social Services
Manitoba	Department of Family Services; Department of Health
Saskatchewan	Department of Social Services; Department of Health
Alberta	Family and Social Services
British Columbia	Ministry of Social Services and Housing
Northwest Territories	Department of Social Services; Department of Health
Yukon	Department of Health and Human Resources

ESTABLISHED PROGRAMS FINANCING

Health services in this country are regulated under the Canada Health Act, which came into effect in 1984. It replaced the Hospital and Diagnostic Services Act and the Medical Care Act relating to standards of services. The Canada Health Act establishes the criteria and conditions that must be in place before the federal financial contribution to health services will be made.

The criteria apply to insured health care services only — medically necessary hospital services, medically required physicians' services, and surgical or dental services that require a hospital for their proper performance. There are five criteria that provinces and territories must meet to receive federal funding: public administration, comprehensiveness, universality, portability, and accessibility.

Public administration means that the health care plan in the province or territory must be administered on a non-profit basis and by a public authority. Comprehensiveness refers to the fact that all services provided by hospitals and medical practitioners are insured. The plan is universal in that all residents of a province or territory are entitled to insured health care services. The waiting period for coverage (e.g., for those who have moved from another province or territory) must not exceed three months; the original province or territory provides coverage for three months after departure.

Portability means that Canadians moving from one province or territory to another continue to be entitled to health insurance coverage. This criterion also ensures coverage when individuals are temporarily absent from their home province or territory. The fifth criterion is access; it refers to the provision of insured health care services without impediments such as user fees.

These five criteria apply to insured health care services only. They do **not** apply to extended health care services such as nursing home care, adult residential care, home care, or ambulatory care — that is, health care provided to individuals on an out-patient basis. Because extended health care services (which include some of the housing options discussed in this study) are not covered by the five criteria, they are not subject to a set of overriding principles.

The Canada Health Act also sets out certain conditions for the receipt of federal funds including the provision of information to the Department of Health and Welfare as required and prescribed in the Regulation. The conditions stipulated in the Act apply to insured

health care services as well as to extended health care services.

While the Canada Health Act sets out the criteria governing the provision of insured health care services, they are actually funded under the Federal-Provincial Fiscal Arrangements and Federal Post-Secondary Education and Health Contributions Act of 1977 (formerly called the Federal-Provincial Fiscal Arrangements and Established Programs Financing Act). Under the Act, which is administered primarily by the Department of Finance, provinces and territories are entitled to equal per capita federal health contributions that are indexed annually in relation to increases in the Gross National Product (GNP) minus 2 percentage points. (The February 1990 budget froze the per capita entitlement for a two-year period and reduced the indexation formula by another percentage point.)

It is of interest that the original funding arrangement required full indexation to GNP increases. The deduction of 2 percentage points from the calculation of annual indexation was introduced in 1986 as a method of reducing federal spending. This type of cost-cutting is a form of deficit reduction not readily apparent to the general public. However, the measure represented a significant reduction in the growth of transfers to provincial treasuries.

The federal contribution is based on the 1975-76 national average per capita costs escalated by population and GNP growth to a current value. In 1977-78, the federal government reduced its income tax rates so that the provinces could raise theirs (at no cost to the taxpayer). The current value of this "tax transfer" is deducted from the total estimated entitlement and the remainder is paid in cash.

In addition to the cash and tax transfers, provinces and territories receive an equal per capita grant to help pay for the costs of extended health care services. The per capita payment of $20 was initially set in 1977-78. This payment is increased annually by the average three-year rate of growth of the GNP minus 2 percent (frozen in February 1990).

Table 7 presents the federal contribution to the provinces and territories for insured health care services for 1988-89. The first column indicates the amount paid as a cash entitlement. The second column is the amount paid in the form of a tax transfer. Total federal cash and tax transfers for these services are presented in column three.

Table 8 outlines the federal contribution to the provinces and territories for extended health care services for 1988-89. The three columns represent the cash payments, tax transfers, and total federal contribution. There is no tax transfer indicated in this table because

the federal contribution for extended health care services is calculated on the basis of a per capita formula that is paid as cash. Table 9 sets out the 1989-90 advance calculations (second adjustment to the advance) for insured health care and extended health care services.

The EPF fiscal arrangement is generally referred to as "block funding" because monies are transferred as a "block" by the federal government to the provinces and territories on the basis of a set formula. As previously described, provinces and territories must meet the five criteria for insured health care services in order to receive the federal contribution. In fact, the federal government has had to impose a financial penalty upon provinces that allowed extra-billing for the provision of insured health services; this user fee practice contravened the access criterion set out in the Canada Health Act.

The use of federal block funds has often been questioned on the grounds that once the federal monies are transferred into provincial and territorial coffers, these monies become part of general revenue that can then be used for other purposes. Block-funding allows more flexibility especially when compared to the CAP cost-shared arrangement in which provincial and territorial governments must pay the first dollar for a specific service, for which they are reimbursed 50 cents by the federal government.

The Canada Assistance Plan has often been criticized on these very grounds — i.e., that it requires provinces and territories to pay the initial cost. This is especially difficult for the less wealthy regions of the country. Poor economic conditions and high rates of unemployment translate into higher costs for welfare and associated services as well as a weaker tax base and more limited provincial budgets. The regions that most need the funds are the ones least able to pay. Although equalization payments are intended to correct this fiscal imbalance, they have not been very successful.

It is of interest that the proposed Child Care Act, which died on the order paper prior to the 1988 election, would have moved the funding of child care services out of the Canada Assistance Plan. Under the proposed funding arrangement, the federal government would have shared more than 50 percent of the costs of child care services for provinces that had a low per capita expenditure on child care. This variable formula was intended to respond to the *de facto* inequity of CAP. While 50-50 is an equitable cost-sharing formula on paper, it is inequitable in practice. At the same time, however, the proposed Act was roundly criticized. By moving funds out of the open-ended cost-

Table 7
Federal/Provincial Fiscal Arrangements and Federal Post-Secondary Education and Health Contributions Act

Insured Health Services
1989-89
(thousands of dollars)

	Cash payments[1]	Tax Transfers	Total
Newfoundland	141 001	115 639	256 640
Prince Edward Island	32 438	26 212	58 650
Nova Scotia	222 682	179 915	402 597
New Brunswick	179 736	145 414	325 150
Quebec	1 131 464	1 950 555	3 082 019
Ontario	2 068 796	2 249 995	4 318 791
Manitoba	276 834	221 015	497 849
Saskatchewan	263 523	205 882	469 405
Alberta	583 539	529 563	1 113 102
British Columbia	797 445	585 387	1 382 832
Northwest Territories	12 988	11 116	24 104
Yukon	6 302	5 402	11 704
TOTAL	5 716 748	6 226 095	11 942 843

[1]Estimated payments to provinces in 1988-89 including prior years' adjustments.

Source: Department of Finance Canada

Table 8
Federal/Provincial Fiscal Arrangements and Federal Post-Secondary Education and Health Contributions Act

Extended Health Services
1989-89
(thousands of dollars)

	Cash payments[1]	Tax Transfers	Total
Newfoundland	27 386	- -	27 386
Prince Edward Island	6 288	- -	6 288
Nova Scotia	43 180	- -	43 180
New Brunswick	34 745	- -	34 745
Quebec	326 020	- -	326 020
Ontario	463 255	- -	463 255
Manitoba	53 451	- -	53 451
Saskatchewan	49 656	- -	49 656
Alberta	117 790	- -	117 790
British Columbia	147 103	- -	147 103
Northwest Territories	2 549	- -	2 549
Yukon	1 238	- -	1 238
TOTAL	1 272 661	- -	1 272 661

[1]Estimated payments to provinces in 1988-89 including prior years' adjustments.

Source: Department of Finance Canada

Table 9
Federal/Provincial Fiscal Arrangements and Federal Post-Secondary Education and Health Contributions Act

Federal Transfers for Health Care
1990 Advance Calculations[1]
(thousands of dollars)

	Cash payments	Tax Transfers	Total
Newfoundland	174 892	131 846	306 738
Prince Edward Island	39 948	30 117	70 065
Nova Scotia	272 094	205 125	477 219
New Brunswick	220 445	166 196	386 651
Quebec	1 376 629	2 222 804	3 599 433
Ontario	2 487 320	2 662 375	5 149 695
Manitoba	332 662	250 786	583 448
Saskatchewan	308 974	232 929	541 903
Alberta	743 634	563 607	1 307 241
British Columbia	964 172	680 157	1 644 329
Northwest Territories	15 605	13 131	28 736
Yukon	7 681	5 988	13 669
TOTAL	6 944 066	7 165 061	14 109 127

[1]Second adjustment to advance.

Source: Department of Finance Canada

sharing that currently exists under CAP, federal/ provincial cost-sharing would have been effectively limited or "capped."

The open-endedness of CAP cost-sharing is, in fact, a major strength especially in these days of tight budgets for social spending. There is no limit to the federal expenditure under CAP if the province or territory has made its contribution in the manner required by the CAP Act, Regulation, Guidelines and policies (e.g., eligibility for social assistance determined on the basis of a needs test; provincially approved agency for receipt of funds under the welfare services provisions).

Welfare costs, which constitute the greatest percentage of CAP expenditure, are determined largely by factors beyond the control of the programs themselves. These factors include high unemployment, changes in federal unemployment insurance policy and increases in refugee claimants. In short, CAP expenditures rise when needs change. The open-endedness of CAP provides the flexibility required to respond to these needs. Despite the open-endedness of the funding arrangement, there are a variety of provincial controls over these expenditures.

EPF, by contrast, is a finite fund because it is calculated on the basis of a set formula. The federal portion will not increase even if the province or territory extends or improves its health care services or introduces new programs. In fact, it has effectively decreased over the years as a result of the reductions in the indexation formula. While the province or territory is free to use the EPF funds at its discretion, it is essentially playing with a declining contribution from federal sources.

Extended Health Care Services

"Extended health care" refers to health care services made available in out-patient settings as well as to a range of services provided in supervised residences. The latter facilities are financed through a combination of CAP and EPF funds, sometimes referred to as the CAP/ EPF interface.

Under the Canada Assistance Plan, the federal government shares in the cost of services, including homes for special care and certain health care services, provided to persons in need. In April 1977, Extended Health Care Services were incorporated under the Federal-Provincial Fiscal Arrangements and Federal Post-Secondary Education and Health Care Contributions Act. It therefore became necessary

to clarify how certain extended health care services would be funded in order to avoid duplication of payment under both CAP and EPF.

The sharing of costs for special care services under the Canada Assistance Plan was modified considerably — in fact, substantially reduced — by the introduction of the per capita block-funded EPF arrangement. Extended Health Care Services under the Federal-Provincial Fiscal Arrangements Act include the costs of institutional services for adults in long-term institutional settings that provide intermediate nursing home care (also referred to as "Type 2" institutions) and adult residential care (known as "Type 1" institutions). The services provided by "former mental hospitals" that qualify as Type 2 or Type 1 institutions are covered as well.

Extended Health Care Services also pay for home care and ambulatory health care services. The per capita payment for home care and ambulatory health care covers both adults and children. Health care services that are not included under the "block" are considered to be non-EPF health costs and are shared under CAP.

The Guidelines define "intermediate care" in Type 2 institutions as nursing and personal care provided under the supervision of qualified medical or nursing staff; assistance with the activities of daily living; social-recreational programs required to meet residents' psychosocial needs; and room and board. In short, three types of services are provided in these settings: medical/nursing care, social services, and room and board care to meet basic living needs. The services are usually provided on a prolonged basis for a period exceeding twelve months.

Residents in this type of facility have a relatively stable but chronic physical or mental illness or functional disability arising from a mental handicap or physical disability. They are generally considered to have little or no rehabilitative potential. The major purpose of the care is to maintain the stability of the individual's condition and the level of physical, mental, and social functioning that has been achieved.

The cost of this form of care is usually quite high because of the type and extent of service provided by a range of professionals including physicians, nurses, social workers, and physiotherapists. These professionals are not necessarily located on site; their services are generally purchased by the institution on a fee-for-service basis. User fees may be charged for these services although these fees may be reduced through provincial subsidy. Individuals who cannot afford to pay may qualify for provincial assistance.

User fees are permissible for this type of service because it is not subsumed within the definition of insured health care. It is an extended health care service and therefore not subject to the access criterion under the Canada Health Act.

An adult residential care facility or Type 1 institution provides personal care services such as life skills or assistance with daily living activities. Most residents in Type 1 facilities have a "physical or mental frailty" due to age, congenital disability, or illness. Supervisory care by trained personnel is also made available, generally on a twenty-four-hour basis. As in the case of Type 2 institutions, adult residential care facilities provide room and board as well as some recreational and other services to meet individuals' psychosocial needs.

While residents of Type 1 facilities do not need direct medical or nursing attention on an ongoing basis (although they may need such care intermittently), most require assistance in caring for themselves. Many are independently mobile with or without wheelchairs or assistive devices. However, most need help with the activities of daily living such as eating, bathing, and dressing.

Once again, the cost of this form of care can be relatively high given the range of services provided as well as the extent of support required (usually around-the-clock care). The user fee may be reduced through provincial subsidy or some other factor such as volunteer contributions or a low mortgage rate provided to a charitable organization.

Prior to the introduction of Extended Health Care Services, the federal government shared under the provisions of the Canada Assistance Plan in 50 percent of the costs of care delivered to eligible adults and children in homes for special care. The introduction in 1977 of block-funding for health care services meant that costs previously shared for this form of care under CAP are now more narrowly defined. They are limited to the combined amounts of provincial and municipal expenditure for the following items:

- a comfort allowance
- a clothing allowance
- non-EPF health care costs
- a portion of the room and board, represented by the difference between the total of the above three components and the maximum monthly Old Age Security/Guaranteed Income Supplement. In December 1989, the maximum amount of these benefits was $337.04 and $400.53, respectively, for a total monthly maximum of $737.57. These benefits are indexed quarterly.

When the aggregate of the first three components is equal to or exceeds the OAS/GIS rate, there is no cost-sharing of the room and board component. In other words, the maximum monthly shareable cost for residential care under the Canada Assistance Plan is the OAS/GIS monthly maximum for a single person, provided that the aggregate of the cost elements of comfort allowance, clothing allowance, and non-EPF health care does not exceed that amount.

This monthly maximum may be exceeded when the individual requires special needs items defined in the Extended Health Care Services Guidelines. In institutional care settings such as Type 1 and Type 2 residences, these items of special need include dentures, hearing aids, eyeglasses, family planning devices, orthodontic appliances, prosthetic equipment, and wheelchairs.

Where the elements of comfort allowance, clothing allowance, and non-EPF health are less than the OAS/GIS maximum, the difference may be made up by the room and board component of the care up to the OAS/GIS maximum. Where all four elements are less than the OAS/GIS maximum, only the actual costs may be claimed under CAP.

Provinces and territories calculate the costs of these facilities on the basis of per diem rates. User fees are then determined. The 1989 user fees for Type 1 and Type 2 facilities set by provinces and territories are outlined in Table 10.

Residents of Type 1 or Type 2 facilities receive a comfort allowance for the purchase of clothing, bus fare, and other small comforts. The comfort allowances provided in Type 1 and Type 2 facilities throughout the country are outlined in Table 11. (It should be noted that comfort allowances have been criticized because their levels are generally so low that they barely cover the costs of a monthly bus pass and minimal clothing requirements.)

While the funding arrangements for extended health care services appear to be complex, they are based upon a relatively simple principle. Costs that relate primarily to room and board, social services, and non-medical care are funded for eligible individuals under the Canada Assistance Plan. Costs that are primarily medical or health-related are covered under block-funded health dollars. Individuals not eligible for CAP cost-shared assistance must contribute to the costs of care by paying a user fee established by the province.

There are two other types of institutional care that qualify for federal cost-sharing: domiciliary residences (Type 0 facilities) and supportive living environments (SLEs).

Table 10
User Fees, Residential Facilities
1989

Newfoundland	User fees are based on an enriched needs test up to a monthly maximum of $1510 for Type 1 and Type 2 facilities.
Prince Edward Island	Full per diem rates are charged: $101- $119 for Type 1 facilities and $36 - $60 for Type 0 facilities. Personal income exemption of $80 a month.
Nova Scotia	Eligibility based on a needs test. Individuals contribute all their income less a personal use allowance of $89 a month.
New Brunswick	Not applicable
Quebec	Maximum of $17.99 a day to $28.96 a day depending upon the facility. Maximum rates are rarely charged. Parental contribution may be charged for children.
Ontario	A Family Benefits recipient pays the difference between the cost of care set by the facility and the FBA payment minus an income exemption. The exemption is $160 a month plus 20% of additional income. Individuals who don't qualify for FBA pay cost as determined by facility. Residents of Community group homes pay $23.30 a day from FBA or private income.
Manitoba	There are no user fees for adult or child institutional homes or adult community residences. Users are charged only in personal care homes. Residents in personal care homes pay $20.90 a day.
Saskatchewan	User fees vary type of facility. For group homes for adults with a mental or physical disability, user fees are $647 a month.
Alberta	User fees are needs tested. The resident pays $14 a day if that person has assets over $1500, and no contribution if assests are less than $1,500. Seperate arrangements are made for out-of province residents, primarily from Northwest Territories and Yukon.
British Columbia	Unable to provide information.
Northwest Territories	$247 to $450 a month for Type 1 facilities. Up to $732.47 a month for Type 2 facilities (calculated according to the OAS/GIS rate). Standard recommended user fee is $350 a month for Type 1 and Type 2 facilities.
Yukon	$11 a day for Type 2 facilities.

Table 11
Monthly Comfort Allowances
Residential Facilities
1989

Newfoundland	$110 (Type 1 and Type 2 facilities)
Prince Edward Island	$50 (Type 0 and Type 1 facilities)
Nova Scotia	$89 min. to $105 max. (Type 1 and Type 2 facilities)
New Brunswick	$110 (Type 1 facilities), $95 (Type 2 facilities)
Quebec	$125 (Type 1 and Type 2 facilities)
Ontario	$100 (Type 1 and Type 2 facilities)
Manitoba	$53.80 (Type 1 facility); $78.20 (Type 2 facility)
Saskatchewan	$60 (Type 1 and Type 2 facilities)
Alberta	Persons in residential facilities receiving the Assured Income for the Severely Handicapped (AISH) receive a handicap benefit of $175 a month. Persons in residential facilities who qualify for social allowance but not AISH receive $56 a month.
British Columbia	Unable to provide information.
Northwest Territories	$125 max. (Type 1 if individual is funded under social assistance); $125 max. (Type 2)
Yukon	Permanent labour force exclusion benefit of $70.

Domiciliary residences provide a living facility for individuals who are relatively independent but who are unable to maintain a household of their own. Their primary need is for housekeeping services. In addition to room and board, domestic assistance made available in these residences includes meal preparation, cleaning, and laundry. This type of facility does not provide any form of nursing or personal care. Domiciliary residences are eligible for cost-sharing under the Canada Assistance Plan.

Supportive living environments (SLEs) offer short-term accommodation, usually of less than twelve months' duration. The primary purpose of such accommodation is crisis intervention, rehabilitation, or social integration. Costs for supportive living environments are eligible for cost-sharing under the Canada Assistance Plan.

This category of residence is not intended for persons with a mental handicap. These residences are intended primarily as transitional homes, not as long-term residences which many individuals would require. The prohibition means that these homes cannot be set up as community-based residences for persons coming out of institutions. The deliberate exclusion of persons with a mental handicap has been considered by some as a discriminatory policy.

Finally, while the EPF block has modified the way in which residential services for adults are funded, CAP continues to share all the costs of residential care for children in need including those with a mental handicap.

Extended Health Care Services also support home care and ambulatory health care. Home care refers to diagnostic, treatment, and maintenance services provided in the home by health care personnel such as nurses, physiotherapists, and dieticians. The installation and operation of equipment required for medical purposes such as renal dialysis are covered as well.

Ambulatory health care refers to direct care provided by nurses, physiotherapists, dieticians, and other health care personnel through a health centre or unit other than a hospital.

Mental health services are excluded from coverage under Extended Health Care Services. In addition, services that are considered to be primarily homemaker assistance are not eligible for health care funding. These are supported under the Canada Assistance Plan when provided to individuals who qualify as in need or likely to be in need on the basis of provincial definition. Homemaker services are shareable under the assistance provisions and/or the welfare services provisions of CAP.

In summary, the EPF block funds health services delivered in a hospital, in a health setting such as local community health centre, or in the home. Extended health care services provided in community residences are only partially funded under the block. The social service component of the care (i.e., comfort and clothing allowances, non-health services, room and board) is shared with the federal government for eligible individuals under CAP. The major federal funding arrangements for health and social services, including various forms of extended health care, are depicted in Figure 3.

Provincial Initiatives

Most disability-related housing and support services are funded with some form of federal contribution under the Canada Mortgage and Housing Corporation, the Canada Assistance Plan, Established Programs Financing, and Extended Health Care Services. Provinces and territories generally try to maximize these cost-sharing opportunities.

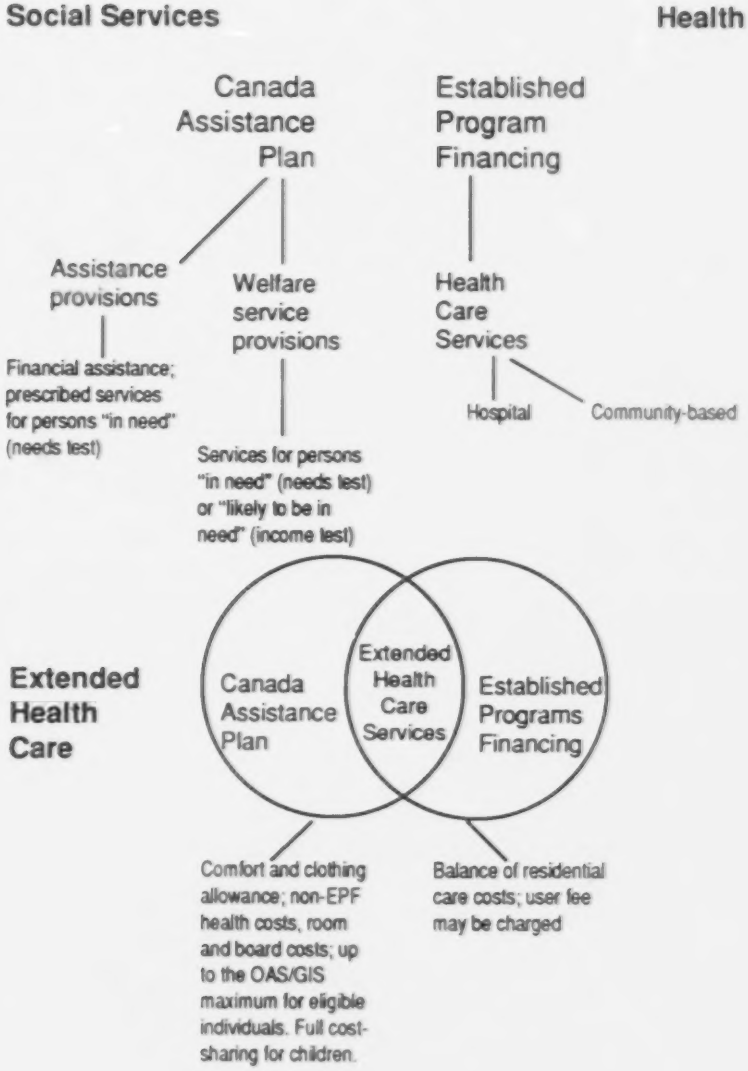
However, some provinces have undertaken initiatives on their own even though these do not qualify for federal dollars. There may be a particular problem that requires an extra infusion of funds or the program may not be eligible for cost-sharing if it does not require a needs test. Some examples of provincial initiatives are outlined below. While these are by no means exhaustive, they illustrate independent provincial activity in the field of disability-related housing and support services.

The Ontario Ministry of Housing has channelled substantial funds into non-profit housing programs over and above the cost-shared dollars it spends on these programs. This is in response to the severe shortage of affordable housing, particularly in the southwestern part of the province.

Quebec provides a cash payment of $101.74 a month (as of January 1989) to all parents with children under the age of eighteen with a severe disability. By contrast, the cash payment provided in Ontario is calculated on the basis of an income test. The level of benefit in Quebec is relatively low compared to the maximum monthly amount in Ontario (up to $300). The trade-off is that the former is provided on a universal basis — i.e., to all parents caring for a child with a severe disability regardless of family income. Ontario provides benefits only to families whose incomes fall below certain levels.

The Alberta Department of Family and Social Services sponsors

Figure 3
Federal Funding Arrangements for Health and Social Services


Social Services
Health
Canada Assistance Plan
Established Program Financing
Assistance provisions
Welfare service provisions
Health Care Services
Financial assistance; prescribed services for persons "in need" (needs test)
Hospital
Community-based
Services for persons "in need" (needs test) or "likely to be in need" (income test)
Extended Health Care
Canada Assistance Plan
Extended Health Care Services
Established Programs Financing
Comfort and clothing allowance; non-EPF health costs, room and board costs; up to the OAS/GIS maximum for eligible individuals. Full cost-sharing for children.
Balance of residential care costs; user fee may be charged

the Handicapped Children's Services Program, which falls under the provincial child welfare act. It is directed toward children under the age of eighteen with a mental or physical handicap. Assistance is made available under an agreement between the director of child welfare and the parents or legal guardians of the child.

Parents receive full or partial reimbursement for the expenditures arising from the disabling condition. Funds may be provided to help cover the costs of a special service (such as day programs), medications, transportation, and relief services such as respite care. Equipment such as wheelchairs, hearing aids, prosthetic appliances, and orthopedic shoes is made available through the Alberta Aids to Daily Living Program. Reimbursement is determined on an individualized basis through negotiation with a caseworker. While the level of assistance varies, the Handicap Children's Services Program is considered to be "universal" in that it is available to all parents caring for a child with a severe disability.

Chapter 4:

The Interaction of Funding Sources

The previous chapter described the sources of funds for disability-related housing and support services. This chapter on the interaction of funding sources examines how funds are directed in varying combinations toward a range of services.

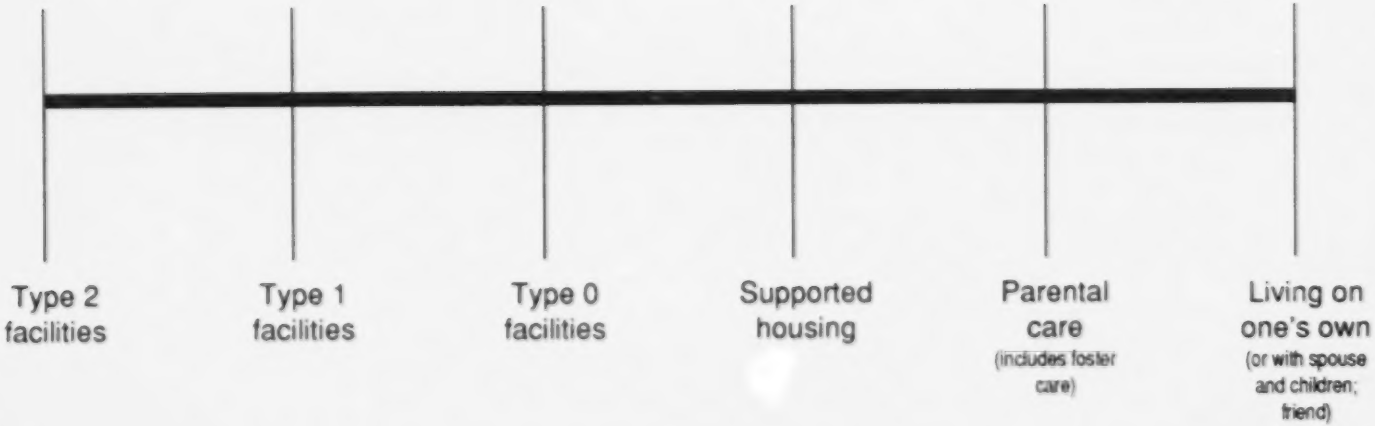
Disability-related housing options have been developed in response to a diverse range of needs. These options can be placed along a continuum that includes: specialized facilities providing intensive supervision or medical care; room and board; and complete independent living in a private home or apartment. The left end of the continuum represents the arrangement in which the most extensive form of care is available. The extent of care and supervision decreases as one follows the continuum toward its right end, the culminating point representing independent living.

While there are many points along the continuum reflecting different degrees and forms of care, there are essentially six major types of residential arrangements that will be discussed here: Type 2 facilities, Type 1 facilities, Type 0 facilities, supported units, parental care (including foster care), and living independently with friends, spouse, and/or children (see Figure 4).

The first housing option at the left end of the spectrum is intended for individuals who require medical, nursing, or health-related care as well as other support services such as life skills training.

The second type of accommodation is intended for individuals who require non-medical supervision as well as training in basic life

Figure 4
A Continuum of Housing Options



skills. Residents of these facilities generally participate in some form of day activity such as a sheltered workshop or vocational training program. While residents may require health-related care, their needs lie primarily in the social and psychological areas.

The next point along the continuum represents room and board arrangements. These are intended for persons who are relatively independent but who cannot function entirely on their own. They require assistance related primarily to housekeeping and daily activities such as shopping and meal preparation. Homes that provide room and board are referred to in the federal cost-sharing guidelines as "Type 0" facilities.

Supported arrangements or units are yet another point on the continuum of possible housing options. Individuals live relatively independently but generally require some form of home support or attendant care service. The services are often delivered as part of a special non-profit housing project or apartment complex. Support staff usually live outside the unit but provide ongoing assistance depending upon the need.

The next step along the continuum is parental care. Many individuals with a disability live with parents or are placed with a foster family that is paid to provide room and board and often other forms of care (e.g., teach basic life skills).

At the right end of the spectrum are individuals who live on their own, with friends, or with spouses and children in private homes or apartments. These persons may require certain forms of support such as homemaker services, attendant care, or assistance with the costs of rent or accessibility modifications.

Individuals may move between the points on this continuum. If they acquire certain skills or can function more independently, they may move toward the right end of the spectrum. Conversely, if their circumstances change (e.g., their medical condition may deteriorate), they may have to move toward the left end of the spectrum to another living arrangement that provides more extensive care.

The legislative and funding bases of each of these points on the continuum are discussed below.

The individuals at the extreme left end of the continuum live in facilities designated for cost-sharing purposes as Type 2 residences. The Canada Assistance Plan shares in the funding of the care component provided by these facilities but only on behalf of eligible individuals — persons who qualify on the basis of a needs test — and only up to

the monthly OAS/GIS maximum for a single person ($737.57 as of December 1989). The OAS/GIS limit may be exceeded for an eligible individual whose special needs (e.g., eyeglasses, prosthetic appliances) would be shareable under the Canada Assistance Plan if the person were residing independently in the community.

The balance of the funds required to support these services is derived from provincial health dollars. (Some provinces, such as Nova Scotia, fund residential care through provincial departments of social service.) Provinces, in turn, receive assistance for the funding of their health services through Established Programs Financing, a portion of which consists of a per capita grant for extended health care services.

Type 2 facilities may be operated by the province, by a municipality or by a non-profit organization. If the residence is being renovated or newly constructed, it may qualify for assistance with the capital expenditures incurred for the residential portion of the program. As earlier described, non-profit organizations may be eligible for developmental assistance. If the project is approved, CMHC acts as guarantor for the mortgage negotiated with a private lender. It also shares with the provincial housing ministry in the difference between the economic rent (i.e., mortgage, taxes, insurance) and the rental revenue.

Revenue in Type 2 facilities is derived from the monthly amounts residents are expected to pay, based on the per diem rate set by the province. Individuals who are not eligible for provincial welfare assistance must contribute to the cost of their care. User fees are permitted because these residences are considered to be an extended health care service rather than an insured health care service within the definition of the Canada Health Act. However, user fees are often less than the actual costs of care.

In some cases, residents in these facilities actually receive a monthly welfare cheque directly from the province. They are required to use these funds to pay their room and board. They can keep the remainder (generally around $100) as a comfort allowance from which they are expected to pay for items such as a bus pass, clothing, toiletries, and recreational costs.

The funding, then, for this type of housing arrangement flows from three major sources:

1. the cost-shared arrangements between CMHC and the provincial ministry of housing (the respective contribution of each is deter-

mined by federal/provincial agreements, the terms of which vary by province) for the residential components of the facility;
2. CAP cost-sharing on behalf of eligible individuals only (i.e., those who qualify on the basis of a needs test) and for certain components of the care (the comfort allowance, clothing allowance, non-EPF health-related costs, and the remaining amount attributable to room and board up to the maximum monthly OAS/GIS, which may be exceeded in the case of special needs items that a particular individual may require); and
3. EPF for the remaining costs of the care. Certain provinces may provide funds over and above the amounts received from the federal government.

The legislative and funding arrangements for Type 1 residences are similar to Type 2 facilities except that the former do not provide the same degree of medical or nursing care. While residents may require medical supervision, they do not need continuous or extensive attention.

This form of care is less costly than that provided in Type 2 residences; as a result, the per diem rate for this residential facility is lower. However, residents still require psychological and social support, life skills training, supervision (usually around-the-clock), and room and board care, all of which make this a more costly care arrangement than Type 0 residences.

Type 1 facilities are eligible for the same form of capital assistance as Type 2 residences: the non-profit sponsor may qualify for help with developmental costs, for a mortgage guarantee from CMHC, and for a cost-shared monthly subsidy to cover the difference between its economic rent and its revenue (derived from the monthly amounts paid by residents). The Canada Assistance Plan pays certain costs of residential care on behalf of eligible residents who qualify on the basis of a needs test. The remaining care costs are derived, in most provinces, from the health budget, which receives a federal contribution through EPF.

The costs of care for children in Type 2 and Type 1 residences remain shareable under CAP. The extended health care funding for residential care does not apply to children.

In most provinces, Type 0 residences refer to group homes. These provide room and board as well as housekeeping assistance. Type 0 residences do **not** qualify for any form of EPF funding because they are

not considered to be extended health care facilities within the meaning of the Canada Health Act. These residences are, however, shareable under CAP.

As previously explained, the federal government will share under the assistance provisions of CAP in the room and board costs on behalf of eligible individuals — i.e., those who qualify for assistance on the basis of a needs test. In addition, some residents may require special needs items such as dentures, eyeglasses, hearing aids, family planning devices, insulin, prosthetic appliances, a bed lift, or a wheelchair. These special needs items are shareable under CAP for eligible individuals.

A non-profit sponsor operating the group home may qualify for cost-shared mortgage assistance as described above.

Supported living arrangements are the next point on the continuum. While "supported living arrangement" is a generic term, it usually refers to a situation in which individuals live in separate units of an apartment or housing complex. Residents live independently; however, there may be individuals employed by the (generally non-profit) sponsor to provide supervision or assistance as required. Support services such as attendant care are also made available through local agencies.

The funding sources for supported housing arrangements vary by province. If residents require financial assistance or have some form of special need, they may qualify for this help under provincial assistance. CAP, in turn, shares 50 percent of the costs.

Homemaker services refer to assistance with activities such as shopping, meal preparation, housekeeping, and banking. These services may be funded under the assistance or welfare services provisions of CAP or both. The province is free to choose the funding route it prefers.

Under the assistance provisions, costs are shared for the services provided to individuals who qualify on the basis of a needs test. The service must be purchased at the request of a provincially approved agency listed in a schedule to the Canada Assistance Plan agreement.

When the service is provided by a non-governmental agency, including both commercial and non-profit organizations, the sharing of the costs is based on the fee charged by these agencies. If the service is delivered by a provincial or municipal organization, the fee cannot exceed the actual cost of providing the service.

Provinces may choose, however, to share costs under the welfare

services provisions of CAP instead of or in addition to the funding arrangement described above. This means that the costs of the services can be shared with the federal government for those "likely in need" based on level of income. Provinces can have a universal program and CAP would share in the costs of the program only for those persons likely to be in need.

In other words, individuals may be eligible for the service if they qualify on the basis of a budget deficit or if they qualify according to provincial interpretation of "likelihood of need." Households whose net income falls below certain levels would be eligible for service on the basis of an income test.

An income test differs from a needs test in that it looks only at sources of income. Liquid assets — bank accounts, insurance policies, stocks, bonds — are not examined. Because the income test is based purely on income and does not probe into other resources, spending patterns, or the amount for basic requirements or special needs, it is easier to administer and is considered to be less intrusive.

As previously explained, a significant outcome of the Federal/Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities was an agreement to consider persons with a disability as "likely to be in need." This means that they may qualify for certain welfare services — i.e., those targeted specifically toward persons with a disability — on the basis of disability rather than on level of income.

Residents may also require some form of attendant care. This refers to services provided by attendants (not usually trained in health care) to assist individuals in performing the activities of daily living, —i.e., bathing, dressing, light meal preparation, eating, toileting, and personal grooming. In some cases, attendants may provide the homemaker services referred to above such as light housecleaning or laundry.

Because attendant care is not primarily health-related, it is not funded through EPF. It is generally supported under the welfare services provisions of CAP. In fact, the welfare services provisions of CAP consider attendant care to be a form of homemaker service whose purpose is to support community living.

Home care, by contrast, involves a significant amount of medical, nursing, or health-related support. It qualifies as an extended health care service and is generally administered by provincial ministries of health.

In most supported residences throughout the country that are not classified as Type 1 or Type 2 facilities, individuals are required to pay a monthly amount for room and board. Persons who are eligible for welfare may qualify for the room and board rates, which may be different from the regular rates of social assistance. The monthly rates of assistance for room and board care allocated under provincial welfare departments are outlined in Table 12.

If the individuals with a disability are welfare recipients who live in a non-profit housing project, their rents are generally set at certain standard levels. Other individuals may qualify for a rent-geared-to-income unit subsidized by CMHC and the provincial ministry of housing. Persons renting a unit in a privately owned apartment may qualify for rent supplement assistance.

The next form of residential arrangement on the continuum involves living with parents or placement with a foster family. The latter arrangement is often used as an alternative to institutionalization, especially for children with a mental handicap.

While the families selected for this form of foster care have volunteered to provide this service, they are paid a monthly amount to cover the costs of room and board, clothing, and other needs. The monthly amounts paid to foster families that provide special care for children with a disability are outlined in Table 13.

Finally, there are individuals who live independently. They may be eligible for the following forms of assistance. If they have little or no income, they may qualify on the basis of a provincial needs test for welfare. The costs of their special needs may also be covered. Homemaker services may be purchased on their behalf if necessary.

The other possibility is that they may be eligible for homemaker services or attendant care if their income falls below a designated level or if the province has decided to consider them as likely to be in need. The province or municipality provides or contracts for the provision of the services, the costs of which may be eligible for sharing under the welfare services provisions of CAP.

Persons living on their own are entitled to all insured health care services as are other residents of any province or territory.

Individuals in private rental accommodation may qualify for rent supplement assistance. If they are homeowners, they may be eligible for a forgivable loan under the Residential Rehabilitation Assistance Program for the Disabled or analogous provincial program such as that available to residents in Quebec. Funds are provided

Table 12
Monthly Rates of Assistance, Room and Board, Single Person with a Disability 1989

Newfoundland	$350 (non-relative); $222 (relative)
Prince Edward Island	$430
Nova Scotia	$365
New Brunswick	$478
Quebec	The needs of persons with a disability are met by the Ministry of Health and Social Services and are not provided for through social assistance.
Ontario	$855 ($28.50 per day)
Manitoba	For persons requiring care and supervision, up to $345 (relative); up to $436 (non-relative). For persons in approved or licensed residential care facilities, rates vary by level of care: $436 (level 1); $487 (level 2); $538 (level 3); $589 (level 4); $640 (level 5).
Saskatchewan	$252 (does not include support services). For persons in licensed or approved homes, monthly rates vary by level of care: $441 (level 1); $558 (level 2); $712 (level 3). For persons in unlicensed homes, rates also vary by level of care: $380 (level 1); $494 (level 2); $650 (level 3).
Alberta	No special rate for hostels as these are not intended to provide for "permanent" boarders. Group home rates vary; generally $430.
British Columbia	Unable to provide information.
Northwest Territories	No uniform rate; depends on community and cost of living. $587 in Yellowknife.
Yukon	$350

Table 13
Foster Care
Special Care Rates
1989

Newfoundland	Up to a maximum of $998 a month for children. Costs for adults are based on individual support needs.
Prince Edward Island	$360-$710 a month
Nova Scotia	$15.70 a day plus a clothing allowance (children). Foster placements for adults with a disability are not widely used; rates vary by municipality.
New Brunswick	Monthly rates of $186.90 (0-5 yrs.), $213.60 (6-11 yrs.) $261.85 (12 and over) plus up to $7.70 a day for children with special needs, depending on the need. No foster placements for adults with a disability.
Quebec	Daily rates of $8.20 (0-4 yrs., $10.11 (5-11 yrs.), $11.87 (12-15 yrs.), 13.73 (16-17 yrs.) plus average supplement of 11.95 a day. $16.76 a day for adults plus an average supplement of $11.95 a day.
Ontario	Individual Children's Aid Societies set the rates. A Toronto CAS provides $16 a day plus an extra $8 a day for special needs. A Barrie CAS provides $27.50- $35 a day for children with a mental handicap. Funding is provided for adults placed with families; agencies set rates depending on supports required
Manitoba	Rates for persons with a mental handicap vary by need: monthly rates of up $457 (level 1); $511 (level 2); $565 (level 3); $619 (level 4); $673 (level 5).
Saskatchewan	Minimum monthly rates of $262 (0-4 yrs.); $299 (5-12 yrs.); $342 (13 and over). Additional amounts are provided for special needs depending on the care required. No foster placements for adults with disabilities.
Alberta	Daily rates of $48.81 (0-1 year); $10.06 (2-5 yrs.); $11.04 (6-8 yrs.); $11.67 (9-11 yrs.); $13.26 (12-15 yrs.); $15.15 (16-18 yrs.). Additional amounts are provided for special needs; these amounts are individually determined. No foster placements for adults with a disability.
British Columbia	Unable to provide information.
Northwest Territories	Maximum of $80 a day plus expenses (children). No foster placements for adults with a disability.
Yukon	No set rate. Rates are determined on a point system ($14 a point) depending on needs of child. No foster placements for adults with a disability.

under these programs for renovations required to improve accessibility.sabled or analogous provincial program such as that available to residents in Quebec. Funds are provided under these programs for renovations required to improve accessibility.

Chapter 5:

Analysis

The previous chapter described the continuum of disability-related housing and support services. The variety of options as well as the diverse funding sources give the impression that there is a full range of services in place and that these respond to a wide spectrum of need.

However, the reality does not match what the theoretical model implies. There are not sufficient services, organizations experience difficulty accessing various sources of funds, and the services themselves are often inadequate or inappropriate.

This analysis considers the problems in the existing housing options and explores the underlying causes. Problems arise as a result of many factors including the fragmentation of service, restrictive eligibility criteria, rigid rules, lack of service, the absence of guiding principles, administrative and attitudinal barriers, the competitive process, and the absence of guiding principles and standards. Some of the identified difficulties relate to certain housing arrangements, such as group forms of care, while others are generic problems common to all the possible options.

FRAGMENTATION OF SERVICE

Every point on the continuum of residential arrangements has a different legislative base and is supported by a unique combination of funding sources. Disability-related housing and support services resemble more the individual pieces of a patchwork quilt than a smoothly

functioning system.

Each option (except for living independently) has its own eligibility criteria and admission procedures. As one moves to the right of the continuum toward greater independence, it becomes more difficult to make the services work smoothly together because each service (e.g., homemaker, rent supplementation, attendant care) is provided under different auspices. The patchwork approach to services results in a complex network of programs which rarely function "in tandem." One mother of an individual with a mental handicap described the frustrations she had experienced in her long and humiliating trip through the labyrinth of services:

> We, [parents who have children with a mental handicap] discovered that we had all been sent down different tunnels just to be sent back again. We would call somebody who was supposed to be the support authority in the community and we'd say: "This is our need." And they'd say: "You're in the wrong place but if you go over to that person and go down that tunnel or go to those services you'll be fine." So you go to that service and you go down another tunnel and there is nothing at the end again. They'd send you to another desk or another office over and over again until finally you had exhausted all the desks or all the tunnels and before you knew it you were standing there by yourself with your son or daughter. And there was nobody that you could turn to. I can remember the day that I went to the person at the Ministry of Human Resources in B.C. who was supposed to be the ultimate authority in giving us something in terms of our son .... only to be told there was nothing she could do. So I went home. There was nowhere else to go ... so I just went home. And we all have that same story. [3]

Not only is it difficult in many cases to pull all the pieces together; sometimes fragmentation means that certain parts are missing altogether. When the missing parts are essential to a person's ability to function, the impact can be profound. For example, individuals are often able to get an attendant to help at home but not at their workplace. All the dollars that may have been spent on vocational training and job placement are virtually wasted when an essential part of the service package is not in place. A group of friends may want to share an apartment with and provide support for a person with a mental handicap. However, the lack of respite services may render

impossible their ability to sustain this arrangement for more than a limited period of time.

RESTRICTIVE CRITERIA

There are a number of problems arising from the eligibility criteria — such as age and conditions — that various organizations establish as requirements for their service.

Most programs are set up to deal with the needs of a particular population. Service delivery is often circumscribed even further by specifying a certain age for qualification. In the case of most allowances and services for children, for example, the definition of "child" generally follows the provisions set out in provincial child welfare legislation (usually less than eighteen years of age). The definition of a dependent child is sometimes stretched (e.g., provincial social assistance legislation) to include a full-time student under the age of twenty-five.

The difficulty for persons with a disability is that the age of eighteen is often an arbitrary cut-off point. In fact, chronological age may have no relation to independence status. Some individuals may live with their parents for many years beyond the age of eighteen either because this is the most suitable arrangement or because there is no other option.

Regardless of the reason for the dependence, the fact remains that the family would no longer be eligible for a special allowance or support service to which they had formerly been entitled. There may be no change in a person's ability to function independently. The service might be discontinued simply because of the recipient's age.

Withdrawal of necessary supports on the basis of an arbitrary rule often discourages families from caring for dependent adult children. Many families are forced to give up because they can no longer cope with the financial and other stresses. The individual with a disability often ends up in less natural, more costly housing arrangements (e.g., a Type 1 or Type 2 residence).

Some would argue that moving out of the parental home at age eighteen is not necessarily a bad thing. Living independently is a desirable goal and it is important that a suitable extrafamilial arrangement be established. Yet family care can always be a temporary option when other arrangements are inappropriate or unavailable. The issue is not the "rightness" or "wrongness" of this particular form of care, but rather the availability of choice that tends to be artificially skewed by

eligibility requirements based on age.

Yet another example of problematic eligibility criteria are the conditions for service set out by some agencies. Participation in a certain program or receipt of a particular benefit may render an individual ineligible for another service. In many instances, the rules make sense and are meant to help prevent duplication. For example, a person receiving rehabilitation assistance under the auspices of a provincial workers' compensation scheme would not be eligible for vocational training under the federal Vocational Rehabilitation of Disabled Persons Act (VRDP).

While policies and eligibility criteria are necessary to manage various programs, many of the rules governing these programs inadvertently create problems. Most group home arrangements, for example, require participation in a complementary day program. While this requirement sounds reasonable and is intended to act as a positive incentive for encouraging community living, it has in fact created serious obstacles for many individuals.

One resident with a mental handicap was told by the sponsoring agency of his group home that he could continue to live there only if he participated in the sheltered workshop run by the organization. Yet this person felt he was capable of more; he made the "mistake" of seeking and finding a job.

Instead of recognizing and rewarding this important move toward independence, the agency effectively punished him by requiring him to move out of the residence. He had become too successful for the criteria. He no longer fit the functional limitations expected of residents. Not only did he have to look for an apartment on the open market (a luxury he could barely afford on a low-paying job), but he also lost the social network that had obviously been a crucial support system in his life.

RIGID RULES

Because many of the group home arrangements are considered to be care facilities or therapeutic environments, the organizing sponsors set out the rules of behaviour or code of conduct to which residents are expected to conform. Some individuals have complained that these so-called homes are no less restrictive than institutions. Unfortunately, residents have no choice but to stay because there are usually no options.

A family interviewed for this study recounted the story of Caroline, their daughter with a mental handicap, who was living in a group home. The rules of the residence required her to be out of the home during the day; she was expected to participate in some form of day program. There happened to be only one vocational program in the region that was suitable to her level of functioning. She was overqualified for a sheltered workshop but was not yet able to assume paid employment.

The family was informed, however, that acceptance to this program was not a *fait accompli*. Caroline had to qualify for admission on the basis of the program criteria. She had to have the right attitude and good work habits (i.e., arriving on time) to be eligible. Even if she had the appropriate attitude and work habits, she would then be placed on a waiting list with many others whose attitudes were also acceptable. There were simply too few spaces in relation to the demand.

The uncertainty of her acceptance to the vocational program placed in jeopardy her housing arrangement. There was nothing that could be done to intervene in the situation; the rule had been set by the board. The family was told that if it did not like the rule, it could go elsewhere — despite the reality that there was nowhere else to go.

For Caroline, who happened to have emotional problems as well, having the right attitude was part of her problem. She did not generally arrive at places on time and her moods were sometimes unpredictable. These behaviours were, in fact, directly attributable to her disabling condition. They were precisely the reason she needed a special program. Yet the program operated as though these behavioural problems were attitudinal. Unless she took steps to "shape up," she was not eligible for this service.

One could argue that the expectations of the program were entirely acceptable — that employers certainly look for the right attitude when they hire employees. The program was simply reflecting and preparing individuals for the real world. Perhaps Caroline was not ready for this kind of functioning. Maybe she really needed a prevocational or life skills program to help her with her behaviour. The problem was that she was too independent for a basic life skills training program. Once again, she did not meet the eligibility criteria. She was simply a square peg that did not fit any of the round holes.

SQUARE PEG SYNDROME

Caroline is by no means the only square peg. There are many square pegs who do not meet the eligibility criteria set by the services. The fact that there are so many square pegs raises questions as to whether the problem lies with those persons who do not fit the services or whether the services themselves are too rigid or unrealistic in their expectations.

These questions give rise to two related concerns. The first is with respect to the reason for this non-fit. How are needs assessed by service organizations? How broadly or narrowly are they defined? To what extent do the persons for whom the services are intended have an opportunity to articulate their needs and to express how best these might be met? On what basis are individuals accepted or turned away?

When agencies report their activities to their boards or funding sources, they identify whom they have served — the numbers and types of individuals — as well as the kinds of services they have provided. They are not required to account for individuals they were unable to assist. Agencies assume no responsibility for and there is generally no documentation of persons who did not fit the round holes, why the match was inappropriate, and how their needs could have been addressed.

The second concern is whether there should be any square pegs at all. The current system is built around services with established eligibility criteria to which potential clients must conform. There is no obligation to change the service in order to respond more adequately to the needs of the person.

Ideally, the individual should be the focal point around whom services bend, adapt, and adjust. The existing system is not geared to help individuals modify services to meet their needs more adequately. Under current arrangements, the programs and services become the standard of functioning (as demonstrated by the "successful" resident who began to function too well for the service). The real standard should be the person for whom these programs and services are intended.

The square peg syndrome is reinforced by a funding system that requires explicit specification of the nature of the service to be provided by a given agency and the type of person to be served. The system then directs dollars toward the service rather than toward the individual.

As previously indicated, there is an exception to this flow of funds. Under the assistance provisions of CAP, services may be purchased on

behalf of an individual in need. However, the services are basically bought for the individual. The funds are not generally directed to the person who could purchase the services that he or she requires. Whether the costs of services are funded under the assistance or the welfare services provisions of CAP, the dollars go to the services.

Health funds provided under EPF are also directed toward insured health care and extended health care services. Federal housing dollars that assist persons with a disability are service-based as well except for the monies available under the Residential Rehabilitation Assistance Program for the Disabled. Even the Rent Supplement Program intended for low-income households attaches the assistance to particular housing units rather than to the individual or family.

The current flow of funds to services leaves people out of the equation. With the exception of welfare, special needs items and cash transfers that some provinces provide to families,[4] individuals receive no direct assistance to purchase the services they require. They may receive indirect (and usually inadequate) assistance through the tax system.[5]

Unless they are independently wealthy or have a reasonable source of income, most persons with a disability do not have the dollars to allow them to act as purchasers or consumers of service. They are "clients" who have no power or control over the way in which services are delivered.

The implications of these funding arrangements are serious. While millions of dollars are spent on disability-related housing and support services, there are countless individuals whose needs are not being met. Individualized funding has been proposed as one solution, although it too has some potential weaknesses especially in terms of its uncertain ability to support an infrastructure of services (see the discussion in the chapter on Policy Options).

NO PORTABILITY

The problems inherent in a system that attaches dollars to services are compounded by the fact that, in some cases, services are attached to other services. That is, certain support services such as homemaker assistance or attendant care are made available only to the residents of a designated apartment, housing complex, or group home.

In most cases, the non-profit sponsor negotiates with an agency to

provide the required support services. While this may be a convenient arrangement for the residents of a particular home, it becomes problematic if they move to a different housing option. The services are not attached to them as individuals but are attached instead to the facility.

A related problem has been identified by individuals who are eligible for attendant care within their own homes. If they are able to find a job, this same service is often not available to them at their workplace.

The Coalition of Provincial Organizations of the Handicapped (COPOH) has identified the potential problems involved in the joint delivery of housing and support services.[6] The Social Assistance Review Committee of Ontario made a formal recommendation in the *Transitions* report concerning the portability of services.[7] This concept calls for the separation of support services from the actual home so that individuals are free to live in the accommodation most appropriate to their needs and abilities. Residents need not be tied to a particular home simply because it is the only way to obtain the required support services.

The residential arrangements found on the spectrum to the right of and including Type O residences basically include housing facilities with supports provided by community agencies (although in some housing projects, services are purchased for the supported units thereby attaching the service to the home). It is primarily at the left end of the continuum — Type 1 and Type 2 arrangements — in which services are tied to the residence. In fact, their provision within the facility is what actually defines them as Type 1 and Type 2 residences.

As previously explained, these residences are supported under Extended Health Care Services with a combination of CAP and EPF block funds. Because most residents of these facilities are expected to stay on a relatively long-term basis (this does not mean that they necessarily should be there), there is little consideration of portability. Individuals must remain in the residence where the services are provided. Many persons would be able to function in less costly and less structured settings if the appropriate support services were more readily available in the community.

LACK OF SERVICE

When the sponsoring agency in the earlier example offered Caroline the choice of going elsewhere, she was really offered no choice at all. In fact, there is usually nowhere else to go. Most programs, residences, and services have long waiting lists.

In some communities, certain types of programs and services do not even exist. In rural areas in particular, groups of individuals with different types of disabling conditions and of varying ages are often placed together in the same residence because it is simply the only available facility that provides care. There are individuals with a physical disability who must drag themselves across the floors of their homes to get from one place to another because there is no attendant care in their community. There are persons who have to pile up food on their beds on Friday evening because their attendant returns only on Monday morning; there is no weekend service.[8]

The scarce supply of services is a serious concern for several reasons. Some people can barely survive without certain forms of assistance. Others are severely restricted in their movement, their activity, or their choice of living arrangement. For still others, the lack of service means that they must accept the service conditions without question because the offer to go elsewhere is not really an offer but a veiled threat to conform or be turned away. From the individual's perspective, there is no control over the process, the rules, or the type of service provided. The client becomes, in effect, a passive recipient.

One of the reasons behind the shortage of disability-related housing options, in particular, is the enormity of the task involved in setting up and running these homes. The volunteer boards and skeletal staff that characterize most non-profit sponsors can manage only a limited number of residences and are thereby unable to meet the potential need.

Another important factor relates to the so-called lack of funds available for the support of community-based services, especially those directed toward families caring for a dependent with a disability. Provinces do make provision for homemaker services, home care, and assistance to these families either in the form of a cash allowance, reimbursement for the cost of certain goods and services, or respite care.

In actual fact, however, these services usually have long waiting lists or are often not available at all. Most services are delivered in a

fragmented way under a variety of auspices. Families have to pull together a service package from several sources, each of which has its own eligibility criteria. Families that do not qualify on the basis of an income test may not receive any services at all even though these may be of a specialized nature that they are unable to obtain elsewhere.

There is a chronic shortage of respite care, in particular, making it difficult for families to cope with the physical, psychological, and financial strains they may experience in caring for an individual with a severe disability. Yet when families are no longer able to handle these strains — when they no longer have the emotional or financial resources to manage — there always seem to be enough funds for extrafamilial care. There are always dollars available to support individuals in an institutional setting or out-of-family arrangement.

RESIDUAL ORIENTATION

The lack of supports for families is illustrative of an important issue: the current legislative and funding bases of health and social services in this country are framed within the residual mould.[9] That is, services are directed primarily toward the alleviation of crises and are provided to a great extent through institutional forms of care. There is little support for less formal and more natural, preventive forms of assistance such as self-help or respite care.

Individuals are generally expected to take care of their needs through their own resources, with the support of families or through private arrangements. Social services come into play when people are in need or likely to be in need. These CAP criteria have been criticized on the grounds that they reinforce the welfare mode of service provision. They require individuals to be in a state of poverty or near poverty[10] to receive assistance.

It could be argued that the welfare services provisions of CAP (as distinct from the assistance provisions) help move the delivery of service away from the poverty orientation. Under the former funding stream, the federal government will cost-share services at relatively generous net income levels.

As previously described, a single person with a net income of up to $13,668 would qualify for full subsidy (October-December 1989; allowable income levels are adjusted on a quarterly basis). He or she would continue to be eligible for a reduced subsidy up to a net income

of $20,508. In other words, as his or her net income rose above the turning point of $13,668, this individual would make increasing contributions toward the cost of the service. Partial contribution would continue until the cut-off point of $20,508: the net income level at which he or she would have to pay the full amount of the service.

The welfare services stream of CAP also allows for the cost-sharing of services for certain populations that have been designated by the province or territory as likely to be in need. This provision could be interpreted to include, in any given community, persons with a disability. The federal government could argue that it casts its net very broadly; its income-tested cut-offs can catch a substantial proportion of these persons. Its target population provision can be used to assist a wide range of individuals.

The problem is that provinces and territories have the leverage to shrink the net in their delivery of services by tightening up on the income guidelines — making them lower than those allowed by the federal government. In this case, the widespread poverty among persons with a disability renders them 'fortunate'; most are poor enough to be eligible for cost-shared services.

On paper, there is nothing to stop provinces or territories from delivering social services more broadly — e.g., setting up a universally accessible respite service for all parents, regardless of their ability to pay, who care for a dependent with a severe disability. In practice, however, there is a significant disincentive to provide services in this way. The province or territory must pay 100-cent dollars for recipients whose net incomes exceed certain levels. The federal government will not share in the costs of services when these are provided to individuals and families whose net incomes exceed the federal guidelines.

Perhaps the more important disincentive in the current arrangements is the fact that funds are provided for problem-oriented services or for programs that compensate for certain deficits such as inability to carry out basic living tasks. There is no cost-sharing for the type of services that are considered to be social utilities or that constitute a social infrastructure such as independent living centres. A block-funded arrangement for social services, which was proposed in the mid-1970s, would have allowed the support of utility-type programs. For several reasons, including cost concerns, the proposed Bill C-57 was never passed into law.

Insured health care services, by contrast, do not have a poverty orientation. Their block-funded status permits a more broadly- based

provision of service. The criteria built into the Canada Health Act also ensure universal access to essential services.

Despite the recent emphasis upon health promotion and prevention, many forms of health care are still residual and institutionally based. Type 1 and Type 2 facilities funded under Extended Health Care Services are cases in point.

LINKING SERVICE TO INCOME

One of the key characteristics of the current funding arrangements is that the provision of social services is linked to income. An applicant must be eligible for these services on the basis of poverty.

If an individual requires a special needs item or service, he or she would likely want to be a welfare recipient or at least to be poor enough to qualify for a range of cost-shared benefits. As previously explained, persons eligible for social assistance on the basis of a provincial/territorial needs test as well as the value of their liquid assets may qualify not only for income assistance but also for special needs items and prescribed services. Financial assistance, items of special need, and certain prescribed services are cost-shared under the assistance provisions of CAP.

Special needs items and prescribed services are sometimes referred to as income-in-kind because recipients would otherwise have to pay hundreds or even thousands of dollars for these disability-related items. In fact, the cost of disability-related goods in particular (medications, technical aids, equipment, prosthetic appliances) can be shared only under the assistance provisions of CAP. These items are **not** shareable under welfare services provisions because they are not considered to be services.

Support services, by contrast, may be cost-shared under the welfare services provisions that allow for the use of an income test to determine eligibility. A number of problems arise in linking service with income in this way.

Income tests are basically a statement of income. They do not inquire into expenditure (i.e., need). Some individuals with a disability may have what appears to be a high income and would thereby be ineligible for service on the basis of their income.

At the same time, they may incur high disability-related costs that significantly reduce their income. Despite the fact that their real or disposable income is effectively very low, they would not qualify for

services funded under the welfare services provisions of CAP. They would either be ineligible or would have to pay a user fee.

A woman interviewed for this study explained that she required extensive supervision as a result of her disabling condition. She had worked prior to becoming disabled and, upon leaving the work force, was eligible for a relatively generous disability pension. This was the good news.

The bad news was that her level of income now exceeded the provincially set income cut-offs, rendering her ineligible for the specialized homemaker services provided to residents of the housing complex into which she was moving. She would have had to pay an extraordinarily high amount for these services on her own. The cost would have left her without sufficient income for rent and other basic living needs.

The organizational sponsor of the housing complex decided to make an exception in this case because of the potentially perverse effect of the existing set of conditions. Unfortunately, the exception could not be made the rule. CAP provisions require service delivery to be linked to level of income. If it makes no sense for this woman to pay the amount that would have been required to purchase these services privately, then it makes no sense for anyone else either. Her private trouble likely represents a public issue in that there are others experiencing the same problem.

This case example places in question the soundness of the underlying funding arrangements, particularly for persons likely to incur high disability-related costs that they must cover on their own. The recent outcome of the Federal/Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities regarding changes to the likelihood of need interpretation may help overcome this problem. (See the discussion in Chapter 3 on Funding Sources.)

Another individual recounted the difficulties he had experienced as a result of tying service to income. He is living in a rent-geared-to-income apartment and is employed on a full-time basis. He pays a housekeeper for several hours each week to help him with essential tasks: getting ready for work in the morning, meal preparation, and light housekeeping. He decided to hire someone privately rather than go through an agency. He wanted to be able to control the schedule and ensure that the housekeeper would be there at precisely the times he needed the assistance (in the early morning).

At the current time, calculations for rent-geared-to-income sup-

plementation are made by deducting from gross income certain compulsory work-related payments, notably Unemployment Insurance premiums and Canada/Quebec Pension Plan contributions. The costs incurred in disability-related employment expenditures such as a housekeeper are not taken into account in these calculations, even though a substantial amount of so-called disposable income cannot actually be used for the payment of rent.

This individual contends that the amount he spends on homemaker service should be deducted from his gross income when determining eligibility for rent-geared-to-income housing assistance. Because of his disabling condition, the service is an essential employment-related expense; he cannot get to work without this help. The fact that it is not deducted means that he must pay a higher rent on the basis of income that is not available for this purpose.

In short, receipt of this particular benefit (rent assistance) is linked to level of income. However, the narrow definition of income does not reflect the fact that persons with a disability may have a lower net income by virtue of essential disability-related expenditures. The higher costs associated with disabling conditions are not recognized. The definition of "net income" employed by income-tested programs does not realistically reflect the actual amount of income that persons with a disability have at their disposal to pay for a particular item or service.

ADMINISTRATIVE BARRIERS

The description of legislative bases presented in the previous chapter highlighted the complexity of current funding arrangements for disability-related housing and support services. Because most community-based residences are run by non-profit associations, these sponsors must pull together the players and funds from various sources into a workable package.

An organization wishing to set up a residence that offers physical accommodation or room and board only will interact primarily with the provincial department or municipal authority responsible for housing in that jurisdiction. However, a residence providing any form of care considered to be a health or social service enters a new level of complexity.

The sponsor must not only negotiate with the designated housing

authority for assistance with the capital costs involved in the purchase, renovation, or construction of the residence; it must also deal with the appropriate provincial bodies responsible for social services and/or health. The onus is upon the non-profit sponsor to bring together the relevant parties to obtain agreement on their funding proposal. Representatives from each of the departments potentially involved must, in turn, obtain internal approval to proceed. These negotiation and approval processes often take place over the course of several weeks or months. In some provinces, this process has been made easier through a number of internal changes. In the mid-1980s, for example, the former British Columbia Ministry of Human Resources became the Ministry of Social Services and Housing, an amalgamation that facilitates, in an administrative sense at least, the development of social housing. Ontario has an interministerial working group at the provincial level. This cooperation has translated into improved communication in some municipalities as well.

In general, however, there are several difficulties that community groups encounter during this negotiation process. Sometimes one funding source will not approve expenditure until there is commitment to the project from another department. The latter may not provide approval until it is certain that there is agreement from the former, leaving the sponsoring organization in a Catch-22 situation.

This buck-passing creates endless frustration as well as serious problems for groups that may lose valuable property while government departments determine their funding priorities. Community organizations are basically competing on the open market for existing housing (if they are purchasing or renovating) or existing land (if they are constructing the residence). This means that if they find a dwelling or a piece of land that is suitable and affordable, they must move quickly to make an offer and begin the bidding process.

The pressure to act is great; the choices for non-profit sponsors are often very limited. Because of cost considerations, they are generally restricted to seeking property in certain neighbourhoods. In urban areas, housing and land are usually cheaper in the suburbs. At the same time, these organizations must bear in mind the issue of general accessibility. Ideally, the residence should be close to public transportation, shopping areas, and recreational, vocational, and health care facilities.

Finding suitable property that is both affordable and close to these amenities is difficult in many centres of the country. Organizations

representing individuals with a physical disability may be even more restricted in their search for suitable property because of the need to ensure accessibility. It may be too costly or impossible to renovate homes with narrow entrances or with several stories. These organizations may have to limit their choice to a bungalow or split-level residence.

ATTITUDINAL BARRIERS

The time imperative becomes all the more pressing when choices of suitable options are so limited. Yet another problem arises in relation to timing. Before purchase or construction of a group residence, the sponsor must get zoning approval from the appropriate municipal body.

This is often more than a rubber stamp procedure. Many sponsors have encountered serious difficulties gaining this approval because of community opposition to group homes. Residents are frequently concerned that their property value will drop with the presence of a group home in the neighbourhood. Others worry about the safety of their children when "strange-looking" and "unpredictable" persons are on the streets.

These attitudinal barriers arise primarily from fear and lack of interaction with individuals with a disability. At the same time, such barriers create obstacles that thwart efforts to integrate these persons within community settings. Many housing projects throughout the country have been scuttled when zoning permission has been refused because of neighbourhood objections.

Attitudinal barriers often manifest themselves as restrictive zoning by-laws that impede the establishment of low-cost and supported housing. For example, by-laws may require that there be no more than four unrelated persons living together in residences in certain communities. By-laws may specify that there be a minimum distance between dwellings in given neighbourhoods, making it difficult to expand a property in order to improve accessibility or to accommodate more residents.

It is of interest that the Canada Mortgage and Housing Corporation has provided financial support to the Federation of Canadian Municipalities, the Canadian Homebuilders Association, and the Canadian Housing Renewal Association to launch a study on regulatory reform. A wide range of land use issues, including zoning by-laws, will

be examined. However, the program has no mandate for implementation. The study will be a resource to Canadian municipalities that may decide to conduct a regulatory review on their own or in conjunction with the relevant provincial ministry.

It is difficult to change community attitudes toward persons with a disability unless they are provided with an opportunity to participate in communities as full and equal citizens. In some ways, the administrative barriers related to government foot-dragging and lack of coordination seem small when compared to the obstacles arising from irrational fears.

COMPETITIVE PROCESS

The responsibility for coordinating housing arrangements and corresponding support services should not lie entirely with non-profit sponsors, many of which operate on a shoestring budget and skeleton staff. The success of a particular project may be due more to the stamina and know-how of the individuals involved in the funding request than on the real need for housing for certain groups of persons.

Clearly, a non-profit organization needs some expertise in the housing field to carry out a project of this kind. The establishment of a housing development is an enormous undertaking requiring an understanding of the real estate market, financial and property management, funding sources, zoning requirements, hiring procedures, staff training, and supervision.

An extensive learning process is often necessary — one that groups are generally expected to undertake on their own. Organizations that are neophytes in the process have a long, hard road ahead of them. In an attempt to overcome many of these administrative barriers, a group of individuals involved in community-based non-profit housing decided at a national meeting held in Edmonton in April 1988 to take action. A small board of directors was mandated to pursue the establishment of a foundation to support community-based non-profit housing.

The purpose of the proposed Canadian non-profit housing foundation is to raise funds and build a resource base of monies and consultation skills to support individual groups. More specifically, the foundation would provide for the exchange of skills and expertise in the areas of community consultation, building design, tenant organizing, man-

agement systems, and other components of community-based housing for low-income people. The foundation would help demystify the complicated processes involved in the establishment of non-profit housing and would provide appropriate guidance to sponsors concerning the negotiation of legal, funding, and administrative hoops.

At the current time, the enormity of the task involved in setting up non-profit housing projects tends to skew the availability of options. Certain voluntary groups have become *de facto* experts; they have learned the "ins" and "outs" of the system. They have developed the required knowledge and expertise and have become the major residential "brokers" in certain parts of the country.

The result is the survival of the fittest. Sponsors experienced in the housing game can respond to needs relatively effectively and efficiently. There is little incentive for them to work with other groups or share information with interested organizations because they are pitted against one another in the fight for limited government dollars.

In some provinces, such as British Columbia, the funding process has exacerbated these organizational tensions. Over the past few years, the province has been emptying its major institutions housing individuals with a mental handicap. A new policy that came into effect in 1987 to promote this process of deinstitutionalization actually requires organizations to submit bids for groups or clusters of individuals designated by the institution as ready to go into a community-based home. The practice not only places agencies against each other in a bidding war; it has also spawned the creation of a parallel system of mini-institutions for discharged persons.

In short, the existing legislative and funding bases encourage a market-oriented rather than a planned approach to housing persons with a disability. Organizations compete for scarce funds. The ones promising the lowest costs are often the winners.

While some provinces have developed plans for the establishment of community residences or have set desirable housing targets, these plans appear to be general guidelines only. In practice, there is a great deal of discretion employed in these funding decisions.

The competition is fuelled by the passive stance that governments have assumed in relation to the funding of community-based housing. They wait to be approached. Governments play an active role only after the fact. They may exempt certain organizations from the competitive screening process or may expedite the approval if they consider the needs of a certain group to be particularly pressing. But

they tend not to assume a leadership role in the establishment of disability-related housing. The result is that residences are established in a haphazard fashion; there is generally no overall plan to guide their systematic development.

While funds may be designated for specific groups, the development of disability-related housing does not appear to follow any blueprint that has been formulated in response to established need. Fortunately, there are some notable exceptions. The Ontario Ministry of Community and Social Services, for example, has made an explicit commitment to the deinstitutionalization of persons with a mental handicap — a commitment that is being effected through the development of five-year plans to facilitate the movement of individuals into appropriate community-based settings.

While the move toward systematic planning is important, the singular focus upon a specific group contributes to the institutional mode of thinking: the grouping together of a population whose members have a certain problem or set of behaviours. Housing and support services for persons with a disability could just as easily be developed on the basis of the needs of those persons as human beings: as people who need a place to live and some assistance with the activities of daily living.

ABSENCE OF GUIDING PRINCIPLES

The discussion of funding sources made clear the fact that certain housing options (Type 1 and Type 2 residences) are considered to be extended health care services. These residences are not subject to the federal criteria that apply to insured health care services.

The absence of criteria for the receipt of federal funds raises questions about the standard of care in these facilities. There are no minimal federal requirements despite the fact that Ottawa contributes a substantial amount for the funding of extended health care services (see Table 8). The lack of explicit minimal requirements also gives rise to equity considerations and the likelihood of great variability in the quality of service provision throughout the country.

ABSENCE OF STANDARDS

One of the shortcomings of the existing service system is the lack of standards linked directly to the absence of guiding principles. In addition, there are few appropriate mechanisms in place for monitoring standards even when these exist (e.g., health care).

What was particularly disturbing to Caroline's family, for example, was the fact that the house mother who was supposed to supervise the three women in the home was not doing her job very well. Instead of helping the women get ready in the morning for their day programs, she would be concerned about getting her own children off to school. There was no formal teaching, even though this house mother was paid by the sponsoring agency to provide personal assistance and instruction to the residents. This individualized attention might have very well been the pre-vocational training that Caroline required. She was not, however, receiving any such instruction.

It is difficult for a sponsoring agency to be aware of a problem of this nature unless informed of the circumstances or unless it conducts regular or periodic spot checks. Caroline's parents had, in fact, notified the agency that this woman was not fulfilling her contractual obligations. The parents were told that it is hard to find staff for such a low-paying and difficult (i.e., unrewarding, frustrating) job. Implicit in the agency's response was the message that the parents' expectations were simply unrealistic and that sometimes certain things just had to be overlooked.

This specific case raises the more general question of how to monitor whether staff or foster parents are carrying out the duties expected of them. How is it possible, for example, to know what kind of life skills are being imparted and how well this work is being done?

There appears to be little concern about questions related to the quality of service. As long as residents are occupied and out of trouble, the agency sees no need to intervene. Because most persons with a disability are deemed to have limited potential, there is little regard for the issue of staff effectiveness. As previously indicated, there are no national guidelines or standards regarding the provision of service in extended health care facilities.

LACK OF CONTROL

The absence of standards means that there are few checks and balances. There are no parameters defining what is acceptable service provision and what is not. This lack becomes especially problematic in light of the fact that recipients have no say in or control over the services.

The lack of control not only impedes self-determination but also gives rise to other serious negative consequences. Individuals with a disability are frequent targets of physical and sexual abuse.[11] Those who live in any form of institutional setting are particularly vulnerable. Victims are usually afraid to tell anyone about the abuse for fear of reprisal. They often feel that no one will believe their disclosure. In other instances, there is simply no one in whom they can confide.

Abuse is an excessive use of power. It is at the extreme end of the spectrum in terms of relationships. While there may not be an actual situation of abuse in a given group home, there is almost invariably an imbalance of power. The potential for abuse therefore always exists.

Regardless of whether staff live in or out of the residence or whether they are full-time, part-time, or casual workers, they are the ones in control. They determine the rules of the house. Residents are basically programmed. They are channelled into activities and programs that staff and other professionals deem to be in their best interest. Opportunities to influence these decisions are rarely provided.

A study of the need for advocacy for vulnerable adults pointed out that:

> *institutionalization, of its very nature, creates vulnerability.* An institutional setting deprives people of a substantial degree of control over their lives and of many of their rights. Residents of institutions cease to make basic decisions and are required to live by rules and regulations that affect every aspect of their daily lives. For example, they are told when to go to bed, when to get up, what they can eat and often what to wear. Control over finances may be taken away, privacy is eroded or non-existent, and they can no longer come and go as they please. [12]

Regardless of the housing option, it is virtually impossible for sponsoring organizations to monitor what goes on at all times. Their ability is further impeded in relation to residents with a mental

handicap or communication disorder that renders it difficult for them to articulate their concerns. Staff (including foster parents) who provide services within a home setting are generally unsupervised.

There are few avenues of recourse if individuals in any of the exemplary residential arrangements experience disrespect, neglect, or abuse. Finding another place to live is not as simple as it sounds. In many cases, individuals are virtually locked into their current housing arrangement because of lack of alternatives or because they need the support services provided in a certain home. Neither is there any consumer control of the organization or the delivery of support services. The problem has been described in the following way:

> Usually an administrator in a service delivery system, not the individual using the service, makes the fundamental decisions associated with service delivery — timing, frequency, personnel, format of delivery, etc. For example, an attendant care service administrator may schedule when individuals get up in the morning, at what time they go to the bathroom, on what days they get a bath, and so on. In the same way, an individual who requires a reader may have no control over when and how long that reader will read. The individual using the service usually has little or no say about who provides their personal services and how the service is done.[13]

Many individuals with a physical disability, in particular, have expressed concern about their treatment by attendant care workers who have been late, disrespectful, or abusive. Again, there is really nowhere to complain; lodging a grievance with the sponsoring agency often results in the "non-advice" of seeking help elsewhere.

This discussion is not intended to imply that all residential care workers, attendants, or homemakers are not doing their jobs well or are abusive with the individuals whom they are supposed to assist. On the contrary, many provide excellent care under very difficult conditions that generally involve low pay and long hours. Training is usually inadequate. The job is often physically and psychologically stressful. The work can be lonely and sufficient time is rarely allowed for support from colleagues.

There is no question that there are stresses associated with the provision of various forms of disability-related housing and support services. However, when situations of non-fulfillment of contract arise, the service recipient generally has no recourse. There are literally

thousands of individuals living in housing arrangements over which they have no control, in which there is nowhere to turn for help, and for which there are usually no alternatives.

LACK OF PRIVACY

Lack of control is not the only problem encountered by residents of group homes. There is frequently a serious lack of privacy; residents' lives are literally an open book.

This "fishbowl" existence is particularly true for persons with a severe disability. The more severe the disability, the greater the likelihood that care will be provided through some form of group arrangement — usually a Type 1 or Type 2 facility because of the economies of scale associated with the deployment of staff. There is little private space for the satisfaction of physical, psychological, and sexual needs.

Unfortunately, the fishbowl existence is public only within the context of the residence. The conditions under which most individuals live are not known to the general public. There is often no recourse if and when difficulties arise.

NO RECOURSE

The lack of recourse is a general problem pertaining not only to housing but to support services as well. The only place to lodge a complaint is with the supervisor or governing board of the sponsoring agency in the case of a private, non-profit sponsor. But there are no counterbalances or watchdogs within the system to guard against abuses.

The legislative and funding arrangements make no provision at any point along the continuum of disability-related housing and support services for review or appeal. By contrast, there is such a system in place with respect to financial assistance (and there will be one in relation to vocational rehabilitation services).

As a condition of cost-sharing, the Canada Assistance Plan requires provincial and territorial governments to have a mechanism that enables welfare recipients to appeal decisions relating to the reduction, suspension, or termination of financial assistance. These appeal procedures vary throughout the country. (They are separate

from provincial offices of the Ombudsman or human rights commissions.)

A number of problems have been identified in relation to these appeal mechanisms.[14] Inadequacies in the current system arise from the composition of the appeal boards, the background and expertise of appeal board members, the difficulties associated with obtaining interim assistance, and the presumption of guilt until innocence is proven.

Despite the weaknesses of the appeal process, a system is at least in place. There is, in theory, some protection for welfare recipients who feel that an unfair decision has been rendered in their case.

It is of interest that one of the outcomes of the Federal/Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities is a new requirement in the federal/provincial agreement signed under the Vocational Rehabilitation of Disabled Persons Act. The new agreement requires all provinces and territories to have appeal procedures in place by January 1990 for individuals seeking vocational rehabilitation services. This requirement will provide recourse for individuals to appeal decisions related to their eligibility not only when applying for goods and services but also throughout the course of their rehabilitation.

Some provincial child welfare acts also have built-in administrative appeal procedures. Parents have a right to initiate a review of a decision made with respect to their child. In Alberta, in particular, this has important implications for the parents of children with a disability. Because the Alberta Handicapped Children's Services Program described in Chapter Three falls under the provincial child welfare act, there is provision for parents to appeal the decisions made regarding the amount and type of service that the province agrees to fund.

This right of appeal is especially important because assistance under the Alberta Handicapped Children's Services Program is made available on a discretionary basis. Parents negotiate an agreement with a worker for the reimbursement of costs incurred as a result of their child's disabling condition. One Calgary parent interviewed for this study described how he went to the Appeal Board not once but twice to obtain the benefits to which he believed the family was entitled on behalf of his daughter with a hearing impairment. These had been denied by case workers whose decisions in both instances were overturned by the Board.

The Handicapped Children's Services Program has a number of

strengths including the fact that it is not a welfare-oriented service. It is universally available to all families that have a child with a disability and it is broad in its interpretation of what it will reimburse as a special cost. As in any discretionary program, however, potential beneficiaries must be aware of the program, must have the personal confidence to negotiate assertively, and must know what to ask for to obtain maximum benefits. It is not difficult to see how such a system could easily give rise to inequities in the benefits that individual families receive.

British Columbia has recently announced an At Home Program that offers assistance with health care services and that provides support to parents caring for children with a severe disability at home. If a request for assistance is denied by the province, applicants to the program may appeal the rejection to an independent panel of health professionals and parent representatives.

Unfortunately, the appeal procedures in the Alberta and British Columbia programs are the exception rather than the rule. Millions of housing, social service, and health dollars are allocated to various programs with little protection of and control by the individuals on whose behalf these funds are spent.

In the area of housing, in particular, provinces have laws governing landlord-tenant relationships and how to handle the problems that may arise when one party is not fulfilling its contractual obligations (e.g., the landlord is not repairing hazardous property; the tenant is not paying the rent on time). The situation is more difficult, however, in cases where the complaint does not arise with regard to a legally defined obligation but in relation to a more nebulous obligation such as the case described below.

An individual interviewed for this study recounted the story of how lucky he was to obtain a unit in a non-profit housing complex. While his apartment is formally defined as an accessible unit, he is unable to use the upstairs and downstairs parts of the home because these are accessible only by staircase. Go write city hall? City hall is the sponsor of this non-profit housing project!

His dilemma illustrates the fact that there is often nowhere to turn when the funding bodies themselves disregard the rules. Besides, this individual was afraid to rock the boat. At least the one room he was able to use was accessible and affordable — a rare combination.

There are few avenues of appeal either through formal appeal boards or judicial forms of review. Judicial review of an administrative decision is a concept embodied in provincial administrative law. The

decision of an administrator who makes a "government-type" decision affecting an individual's status (e.g., legal guardianship, involuntary/voluntary mental health patient) or rights (e.g., security of person, liberty) is subject to judicial review. This means that an individual can request the court to quash the administrative decision. In the case of a decision made by an official or tribunal, the court can only determine whether the decision was right, wrong, or procedurally unfair and then remit it for reconsideration. The court cannot substitute its own decision.

Judicial review is rarely successful, however, in cases involving residential rules or placement decisions (e.g., sending an individual from an institution to a community-based group residence). In theory at least, the individual is always free to leave the residence. The fact that he or she may have no funds to do so or has no other choice is irrelevant. The point is that there is no legally binding requirement that commits the person to that home. In addition, placement in a group home or facility is regarded more as a service than as a right, a privilege or an incident of status that has in some way been disregarded.

NEED FOR CHANGE

This analysis highlights the inadequacies of the current system of disability-related housing and support services. It considers why changes to this system are urgently needed. Various policy options and their funding implications are examined in the next chapter.

Chapter 6:

Policy Options

The current system of disability-related housing and support services in Canada is in need of repair. The preceding analysis highlighted many of the problems arising from the existing arrangements. This chapter on Policy Options considers some of the ways to improve these services so that they are not simply houses but homes as well.

In searching for possible policy options, the analysis made clear the fact that the traditional response of "throwing dollars" at a problem — providing funds for more of the same — is not an appropriate solution. An infusion of dollars may alleviate the supply shortage but would have no impact upon many of the other weaknesses earlier identified including lack of control, portability, and no recourse. Neither would it fundamentally alter the nature of the residual mould within which current services are framed. As discussed in the analysis, the residual mould refers to the fact that existing services tend to be directed toward the alleviation of crises rather than toward preventive, more natural forms of support.

If more of the same is not an entirely desirable solution, then new directions must be sought to improve disability-related housing and support services. A set of principles is required to identify the objectives to be achieved. The articulation of such principles will help guide the development of a revamped system and point to the corresponding funding requirements.

For the past few decades, individuals with a disability have been engaged in an active and vocal struggle to live in communities like other citizens; to be accepted and respected as full and equal partici-

pants in society. Their efforts have been bolstered by the declaration of the International Year of Disabled Persons in 1981, by the adoption of the Canadian Charter of Rights and Freedoms in 1982 and, more generally, by the growth of the self-help and consumer movements throughout North America.

There have also been many important changes over the last decade in relation to persons with a mental handicap in particular. Several provinces have made commitments to close institutions. More schools are integrating children with special learning needs within their classrooms. The province of New Brunswick, in particular, enacted legislation requiring the integration within the regular school system of students with any type of disability. In 1987, the Canadian Association for Community Living issued the *Community Living 2000* document that sets out a vision of realistic and achievable goals to ensure that persons with a mental handicap participate fully in Canadian society.

There have also been countless recommendations put forth by consumer groups, parliamentary committees, government departments, and voluntary organizations with respect to improving the living conditions of persons with a disability. Most of these independent efforts form part of a larger philosophical objective that seeks the achievement of three major principles: inclusion, citizenship, and self-determination.

PRINCIPLES

Inclusion

The principle of inclusion refers to the opportunity for persons with a disability to participate fully in all of the educational, employment, consumer, recreational, community, and domestic activities that typify everyday Canadian society. The House of Commons Committee on the Disabled and the Handicapped made explicit reference in the *Obstacles* report to full participation as a fundamental principle.[15] The vision put forth in *Community Living 2000* calls for a society in which the lives of persons with a mental handicap are characterized by rights and freedoms. The document makes reference to "membership" and to "belonging to families, friends, neighbourhoods, schools, places of work and the community" — in short, inclusion in all aspects of a community

and society.[16]

One of the ways of achieving the goal of inclusion is through increased support of generic services rather than specialized or segregated services intended only for members of certain groups. For example, education systems funded with general tax dollars should accommodate individuals with a disability. Transportation modes should be accessible to all citizens including those with any form of disability. Communication systems should consider the needs of all persons including those with a visual or hearing impairment or mental handicap.

The principle of inclusion can be realized by spending on fields such as education, employment, transportation, and communications. Most of the funding arrangements for disability-related services do not support more "natural" systems in the form of generic services. CAP dollars, in particular, are directed primarily toward segregated services delivered through social agencies.

While there is no doubt that these specialized services are essential for some people, the problem is that there is no cost-sharing available for the kinds of activity that help individuals with a disability gain full and equal access to public goods and services. The CAP guidelines for cost-sharing under the welfare services provisions explicitly preclude activities related primarily to education, health care, recreation, corrections, job creation, cultural activities, and mental health.

The welfare services provisions also require that services be delivered by a "provincially approved agency" that must meet several criteria. For example, the agency must deliver some form of assistance and/or welfare service as defined by provincial law. Again, these definitions exclude activities in fields such as education and transportation.

A final difficulty with respect to cost-shared funds for activities and services that support the principle of inclusion was pointed out by the Ontario Social Assistance Review Committee:

> There may be problems, for example, in obtaining cost-sharing when the jurisdiction delivering the service is a mainstream jurisdiction. Accordingly, a specialized transportation service targeted specifically to disabled persons would not be sharable if delivered by the ministry that provides transit services to all persons. Similarly, a support service such as attendant care would not be sharable if delivered in an educational environment by an

educational institution.[17]

The problem arises from the fact that cost-shared funds for services under the Canada Assistance Plan, in particular, are provided only on behalf of individuals who qualify on the basis of a needs or income test. As previously explained, the assistance provisions require that need for cash assistance or a prescribed service be determined through use of a needs test. The welfare services provisions require that need be determined on the basis of a needs test or that likelihood of need be established on the basis of a needs or income test. The latter provisions also permit the use of proxy measures to establish likelihood of need.

Generic services, by definition, are intended to serve all members of the public and do not require eligibility to be established on the basis of either need or income. This means that services provided to all members of the public would not qualify for CAP cost-sharing because these services do not carry out the necessary eligibility screening.

By contrast, health care programs that are supported through the EPF block-funding arrangement are generic services. To a large extent, they are able to meet the health care needs of persons with a disability. These services fall short, however, in two important areas: 1) the provision of medications, and 2) the availability of disability-related equipment and prosthetic/orthotic devices for persons who require these medications and this equipment for daily functioning.

Chapter Three on Funding Sources explained how special needs items are provided to eligible individuals. These goods are cost-shared under the assistance provisions of CAP. Medications and special equipment are items that many individuals with a disability require to participate fully in everyday life — sometimes simply to survive. Yet the current funding arrangements place special needs items and services within a welfare mode in which only individuals poor enough to qualify are eligible to receive these forms of assistance.

Notable exceptions to the welfare mode of service provision are the provincially supported drug plans in Manitoba, Saskatchewan, and British Columbia. Each plan has a deductible amount that must be paid by the individual; the province then reimburses a certain percentage of the excess costs. Saskatchewan, Alberta, and Ontario operate the Aids to Independent Living Plan, the Aids to Daily Living Program, and the Assistive Devices Program, respectively. In the latter case, the required 25 percent personal contribution has caused financial hardship for many individuals. The Ontario Social Assistance Review

Committee recommended substantial improvements to this program.[18]

Despite their weaknesses, these programs illustrate the way in which monies can be spent on generic service provision rather than on residual mode funding through the CAP route. These programs provide support for special needs (e.g., medication, aids, and equipment), allowing individuals with a disability to participate in everyday activities.

In short, funds to support generic services are not widely available under current cost-sharing arrangements (except for health care services provided to all members of the population). This means that funds that support the principle of inclusion would have to be sought from provincial treasuries or, on a more limited scale, from federal Secretary of State dollars targeted toward citizenship activities. A final funding option is the pursuit of some new form of cost-sharing agreement discussed below.

Citizenship

"Citizenship" is the second principle that must be pursued as part of a vision to reform the system of disability-related housing and support services. This principle refers to a respect for rights and freedoms. It implies participation in and contribution to a community and to society in general. Citizenship also means equality — that all members have equal opportunity to participate in and contribute to society.

One of the fundamental aspects of citizenship is the opportunity to live in an environment that allows choices and involvement in decisions about everyday living. Citizenship is threatened in residences such as institutions, hospitals, group homes, and other facilities that congregate people, segregate them from the mainstream of the community, and remove opportunities for decision making.

In this country, most children live at home with their parents. Most adults reside on their own or with their spouse and/or children. They may also live with friends, roommates, or other family members. In short, they share a home with people with whom they have significant emotional ties — not with individuals who have similar health conditions or physical characteristics. Persons with a disability, by contrast, are expected to conform to a different set of norms; to live with groups of unrelated strangers who "behave" in a similar way and who

have common problems, diagnostic labels, and treatment plans.

Most adult Canadians live in a home and purchase or obtain the goods and services they need from a variety of sources. They buy their food in one location. They generally work in a setting outside the home. They go to a local physician, health centre, or clinic for health care. They may participate in recreational programs at different facilities throughout the community. Most Canadians do not use their home as a therapeutic environment, quasi-health care clinic, or training ground.

For persons with a disability, however, these functions are combined. Some housing options take the form of mini-institutions (exemplified by Type 1 and Type 2 facilities) in which support services are housed in the residences themselves. In fact, the in-home provision of service is what actually defines these as Type 1 and Type 2 facilities. Even community-based residences often have an institutional quality because physical care (eating, dressing, bathing), health care, skills training, social-recreational programs, and spiritual activity are all carried out at the same place.

The problem that must be addressed is how to ensure that individuals' freedoms are not lost because they have a special physical, mental, or psychological need. Their need for support should not be equated with placement in an institutional or congregate care facility. These persons simply have different living requirements.

Differences in need should be officially recognized in policy. Services must be developed in response to those differences. While responding to differences in needs, disability-related housing and support services must also parallel the living arrangements of the majority of Canadians who have a say in where and how they live and in the activities that comprise their day.

Part of the solution may lie in separating from the actual residence the goods and services that individuals require to meet their basic and special needs. The principle of "functional separation" should apply wherever possible and should help point the way to relevant policy options. In other words, services for persons with a disability should be structured along the same separation of functions that prevails in equivalent systems for other people. Functional separation implies a certain directionality to the expenditure of funds. The unquestioned transfer of dollars toward any residence just because it happens to be "community-based" is simply not appropriate.

In practice, this means a redirection of funds toward the right end

of the continuum — toward those forms of housing that most closely resemble the variety of options normally available: supported housing units, parental arrangements, and living on one's own. This translates into the funding of housing options that are not primarily of the group home genre, unless such residences can ensure that citizenship, in the broadest sense of the term, is protected and enhanced.

It is important to acknowledge that there will always be individuals who require a substantial amount of support or intensive nursing care. The more highly structured residences on the earlier-described continuum may be essential for some people. Despite the need for the extensive care made available in Type 1 and Type 2 facilities, these residences should be not be seen as the only possible options within which this form of care can be provided. Even individuals who require extensive assistance can function in less costly housing arrangements when the appropriate support services are in place in the community.

This can be made possible through an explicit redirection as well as infusion of funds into housing options that provide appropriate choices to respond to differing needs. Funds could continue to be directed toward group homes, but only if the allocation of dollars is tied to standards that require these homes to embody the principles of inclusion, citizenship, and self-determination. There is precedent for tying standards of service delivery to the receipt of federal funds in the form of the five criteria of accessibility, universality, comprehensiveness, portability, and public administration set out in the Canada Health Act for health care services.

Self-Determination

Self-determination is the third fundamental principle that should guide the reform of disability-related housing and support services. The concept of self-determination has been used widely in many differing contexts. It generally refers to valuing people in a manner that ensures they have control over the decisions that affect them, over the policies that influence their lives, and over the programs that have been set up to meet their needs.

The discussion paper on mental health issued by Health and Welfare Canada, *Mental Health for Canadians: Striking A Balance*, reflects the importance of self-determination. It refers to the fact that mental health is improved when individuals acquire skills and re-

sources that enable them to meet personal needs, contribute to communal life, and improve the environment.[19] With respect to persons with a mental handicap, in particular, *Community Living 2000* states that the lives of these individuals should be characterized by self-determination or "having an active and decisive voice in decisions which affect their lives." [20]

The principle of self-determination is particularly relevant to persons with a mental handicap, many of whom are unable to articulate their needs and interests. A study of decision making in community residences found that persons with a mental handicap were much less likely than other group home residents to be involved in making decisions about daily living situations pertaining to meals, recreational activities, and personal relationships with family and friends.[21]

Ideally, individuals should be involved to the greatest extent possible in decisions that affect them. In group facilities, in particular, most residents have little say in even the most mundane of decisions: what to eat, what to wear, when to go to sleep.

One of the means of translating the principle of self-determination into concrete action is to ensure that supports are in place that allow individuals to gain control over their lives. This means that there must be sufficient support services to help them function as independently as possible. It also means that the recipients of services must have a say in how these services are provided. Support services should be developed in direct response to need; individuals should not have to fit the service criteria in order to qualify for support.

At the very least, self-determination means that the expenditure of funds for services should be based upon a negotiated contract involving three key parties: the individual and members of the personal support network (described below), the government representative, and the service provider. This "contract" then becomes operational through the assignment of dollars to the service plan.

Individuals are also empowered when they have access to accurate and up-to-date information that helps them make informed choices. Self-determination is enhanced when individuals have recourse to question decisions that have been made with respect to their lives. Finally, policies that promote consumer participation in the day-to-day operations of a service and that call for representation of consumers on agency boards and committees are supportive of self-determination.

FROM PRINCIPLES TO PRACTICE

Given that the principles of inclusion, citizenship, and self-determination should constitute the framework for policy decisions, there are two questions that must then be addressed: 1) how can these principles be embodied within specific policy options, and 2) how can current arrangements be modified in order to meet more adequately these ideals?

An earlier chapter described the system of disability-related housing and support services as a continuum along which individuals are expected to move as their needs and circumstances change. A fundamental aspect of comprehensive reform is the recognition that even a continuum of services is a professionalization of sorts. A continuum implies that individuals can move along the various points only when they behave according to acceptable standards and that only a professional can determine when a given person is ready to make that move.

A continuum can be problematic as well in that it tends to lock individuals into step-by-step service structures that range from the most to the least segregated. It is then assumed that only persons with limited or moderate support needs can move to the more independent options. "Once located along the service continuum a person must 'learn' his or her way out of that point and into the next, less segregative facility or program .... One's progress for full participation as valued members of the community will be determined by his or her present location along the service continuum."[22]

Group home residents interviewed for this study pointed out that they are often expected to adapt to rigid schedules and sets of behaviours to prove that they are capable of moving to the next level. This requirement for adaptation blatantly and fundamentally violates the principles of inclusion, citizenship, and self-determination.

A service system that embodies these principles would consist of three major components: housing options that meet residents' needs, support services, and personal supports. While these are discussed below as separate components, they are really interdependent elements of a comprehensive disability-related service system. The success of one component depends upon the effective functioning of the other two parts.

Housing

To put in place a range of housing options that promote inclusion, citizenship, and self-determination, the shelter component of the service system must be more actively supported. Separating the funding of shelter from the funding of support services removes the need for individuals to have a particular problem in order to be "eligible" for a place to live or to demonstrate appropriate behaviours before they can "graduate" to another step on the continuum. The housing arrangement is no longer the vehicle for the delivery of services, but rather the structural basis of a home that provides a stable and secure living environment.

There are essentially two types of action that can be taken to make available more housing options, bearing in mind the fact that most persons with a disability have low incomes. First, there must be increased support for the supply side of the affordable housing market in the form of non-profit and cooperative housing. Second, there must also be increased support for demand-based solutions that supplement individuals' ability to pay the costs associated with the rental or modification of housing. Each of these initiatives is discussed below.

It should be noted that, under the current arrangements for social housing in particular, it would not be possible to increase activity in both these areas. Every year, provinces and territories receive a fixed federal allocation for social housing. This means that the enhanced funding of one stream would result in decreased funding of the other stream unless there were an absolute increase in the total "pie" of federal/provincial housing dollars or unless provinces decided to undertake their own housing initiatives.

In times of fiscal restraint, it may not be possible to obtain new funds. *It is entirely possible, however, to obtain funds through a well-planned redirection of expenditure.* For example, funds being spent on expensive forms of institutional care, including both large institutions and smaller Type 1 and Type 2 residences, could be better directed toward community-based housing options and associated support services.

Supply of Affordable Housing

There is a shortage of affordable housing not only for individuals with a disability but also for all low-income persons. The problem is compounded, however, for the former individuals because of their need for accessible as well as affordable housing. While "accessible" generally refers to structural modifications that are made to accommodate certain physical needs, the term has much broader application. For persons with a mental handicap, in particular, "accessible" means being close to public transportation, schools, vocational programs, places of employment, recreational facilities, and other services that they may require.

The supply of low-cost housing has been squeezed as a result of a number of factors including: the skyrocketting costs of land and housing especially in urban core areas; the conversion of low-cost housing stock to expensive luxury apartments and condominiums; and the deinstitutionalization of individuals from facilities for persons with a mental handicap, psychiatric hospitals, and other long-term institutions. The result is an increased demand for affordable housing.

While the shortage of low-cost housing is not new, it has become acute in recent years as a result of these economic and social factors. Another difficulty arises from the fact that much of the low-cost housing has been developed in suburban and outlying areas, creating different sorts of access problems particularly for persons with a disability. They become handicapped with respect to transportation rather than with respect to housing.

The solution to creating more affordable housing options for individuals with a disability lies in addressing the broader issue of the supply of low-cost housing. The supply problem requires a multifaceted approach including increased support from all governments for non-profit and cooperative housing. It means an infusion or a redirection of funds into federal/provincial cost-sharing arrangements that support social housing (described in Chapter 3 on Funding Sources). At the federal level, the need for "new" dollars would require an increased allocation by cabinet to the Canada Mortgage and Housing Corporation, which would, in turn, distribute these funds to the provinces and territories. Additional (unilateral if necessary) provincial activity is also needed to assist communities experiencing a critical shortage of low-cost housing.

More money to increase the supply of affordable housing is not,

however, sufficient on its own. There must also be improved coordination among the various levels of government and between departments within the same level of government; municipal cooperation and support in relation to zoning by-laws as well as service infrastructures such as sewers, roads, and public transportation; the development of affordable land use policy with associated funds to support the implementation of such policy; and a service system that actively strives to embody the principles of inclusion, citizenship, and self-determination.

Problems arising from the lack of interministerial coordination need to be more adequately addressed, especially since the viability of independent housing options depends upon the availability of a range of support services. Provinces should take the initiative to ensure that the responsibility for reviewing housing projects is delegated to a clearly designated body representing all relevant ministries. Ideally, this interministerial collaboration should be replicated at local or regional levels in order to simplify the negotiation processes for the non-profit sponsors.

Municipalities can play an important role in promoting non-profit housing by ensuring that their zoning by-laws do not impede the establishment of non-profit and cooperative housing. In the long term, the problem of restrictive zoning by-laws may resolve itself if the housing options developed by non-profit sponsors move from group forms of care to more natural housing forms.

Supported units could be scattered throughout a housing complex or apartment building, making them subject to the same municipal by-laws as other residences. There could even be a requirement that non-profit and cooperative housing projects designate a certain number of units for persons with a disability. This requirement would apply not only to individuals with mobility impairments but to persons with other types of disability as well.

A recent Ontario initiative is the development of guidelines requiring municipalities to provide a designated amount of affordable housing. The housing land-use policy states that municipalities must ensure that 25 percent of new houses be built for low- and moderate-income households. "Low" and "moderate" income are defined as households that fall in the bottom 60 percent of wage earners in a given area. While this is a positive development for all low-income persons, including individuals with a disability, municipalities are concerned that the guidelines have not been accompanied by increased funding to

offset the costs of the infrastructure, water treatment, and other services required to support such development.

Finally, there is a need for support services that actively strive to embody the principles of inclusion, citizenship, and self-determination. The current system of disability-related housing and support services is passive and largely ineffective. The analysis in the previous chapter made clear the fact that this system requires fundamental reform. Ideally, a service system should be more than an administrative entity or a simple purveyor of services. It should actively pursue a certain vision or set of objectives. Support services are discussed more fully below.

Demand for Affordable Housing

While it is absolutely essential that the stock or supply of low-cost housing be increased, the affordability problem can also be addressed through a number of actions that support the demand side of the equation or individuals' ability to pay housing costs.

Support for both the supply and demand are important. On the one hand, there has to be an adequate supply so that low-income individuals and families have something to purchase. At the same time, the supply-side option is a long-term solution that cannot by itself meet pressing housing needs. The affordability problem can be addressed in an immediate way by supplementing individuals' capacity to pay for their shelter.

Demand-side funding could translate into one of four policy options: 1) an improved Rent Supplement Program; 2) a subsidy or refundable tax credit for low-income renters; 3) more adequate shelter allowances in the basic needs components of welfare benefits; and 4) an enhanced Residential Rehabilitation Assistance Program for the Disabled.

1. Rent Supplement Program

The Ontario Social Assistance Review Committee recognized the potential of demand-side funding by recommending that the Canada Mortgage and Housing Corporation and the provincial Ministry of Housing significantly increase their support of the Rent Supplement

Program in that province.[23] The federal Task Force on Program Review also encouraged more extensive use of this program to redress the imbalance in funding that is heavily weighted toward supply-side options.[24] Yet the current design of the Rent Supplement Program is flawed in that the subsidy is attached to particular housing units into which individuals must move if they are to receive any assistance.

Provinces arrange with private landlords for a certain number of rent-geared-to-income units, in effect designating them as rent-assisted units. If the individual, for whatever reason, moves to another location, he or she loses the subsidy and has to apply once again for a subsidized unit. The program actually locks people into their current living arrangements.

A more portable option would be to assist the *household* so that any family that falls within the specified income levels would automatically receive assistance. The problem from a funding point of view is that a portable supplement, which could be in the form of a tax credit as discussed below, can be very costly.

If, for example, the income cut-off level for eligibility was relatively generous (e.g., around the current average industrial wage of $27,000), then a large number of working poor Canadians would qualify. One way to reduce the potential expenditure is to make the income cut-off level relatively low and thereby "catch" fewer people. Another possibility is to require verification of disability in order to qualify for the proposed credit. The current disability credit is a prototype; it requires medical certification of disability before individuals can qualify. In general, however, it is easier to control the costs of supplementing a fixed number of housing units than of paying cash to an entire group of people who fall within a certain income band.

In addition to portability problems, another limitation of the current Rent Supplement Program is that it does not work very well in tight rental markets. Landlords have no need to enter into rent-geared-to-income agreements when they have a line of prospective tenants at the door. More important, a tight rental market is really indicative of a short supply of rental accommodation. The housing problem in certain communities would be more appropriately addressed through a supply-side option. While these inherent difficulties do not minimize the value of the Rent Supplement Program, they nevertheless point out its limitations in certain housing markets.

2. Tax Credit

Assistance for shelter costs could be provided as an income-tested grant for which individuals would apply. The grant could be cost-shared by the federal and provincial governments. However, unlike the current Rent Supplement Program, the benefit would go to the household rather than to the unit of housing.

Financial help for rental costs could also be provided indirectly as a refundable tax credit. The tax system would act as an "after-the-fact" income test by directing the largest benefit to those at the lowest income level. The benefit would decrease as income rose until the net income reached the break-even point: the point at which benefits would end.

A national rent tax credit would represent a substantial expenditure to the federal treasury unless each provincial government shared in the cost of a national scheme or instituted its own rental assistance tax credit. Some provinces have already implemented demand-side housing assistance. New Brunswick provides a shelter subsidy to low-income renters while the provinces of Quebec, Ontario, and Manitoba make available refundable property tax credits.

The disadvantage of a tax credit is that it generally provides assistance in the form of a lump sum payment. Ideally, the tax credit would be paid more frequently, perhaps four times a year.

3. Improved Welfare Benefits

Recipients of welfare, in particular, experience hardship because the allowances designated for the shelter component of the basic needs budget are inadequate in most provinces. A study of Alberta welfare recipients, for example, found that 53 percent were paying more than the maximum levels designated for shelter and utilities.[25] The average extra amount was $80 per month, which they had to take from their food allowance. A report on the adequacy of housing budgets for welfare recipients in Winnipeg concluded that the amounts allocated for shelter are not keeping pace with the costs of private housing.[26]

A study of income assistance in British Columbia assessed the adequacy of current benefits in relation to the costs incurred by various family units.[27] Examination of the shelter component for five hypothetical family types found a significant shortfall between the actual

average cost of shelter and the current shelter allowance ceiling set by the welfare system. The shortfall ranged from 14 percent for a two-parent family with two children (ages five years and six months) to a 61 percent shortfall for a single male household. See Table 14. (Details as to how these calculations were made as well as cautionary notes regarding their interpretation are outlined in the report.)

In response to the affordability problem experienced by welfare recipients, the Social Assistance Review Committee made several recommendations concerning the adequacy of Ontario's shelter allowance. The Committee proposed that the actual average cost of shelter be established as the shelter reimbursement ceiling. It further recommended that a core rate should be set for the province as a whole. This amount would be supplemented by a second-tier subsidy for regions of the province with higher shelter costs.[38]

The province of Ontario responded to the Committee's recommendations by announcing, in May 1989, a package of reforms worth $415 million. Of this total, $120 million was designated for improved shelter allowances and another $20 million for utility costs.

The report of the Welfare Assistance Review Committee of Prince Edward Island expressed concern about the shortage of low-cost housing in that province.[39] It recommended that current shelter ceilings be raised by an amount equal to the rent increases allowed since 1986 by the provincial Rentalsman. It further proposed that future shelter ceilings be established in relation to the actual cost of low to moderately priced housing units of acceptable standards and that these ceilings be adjusted annually in accordance with the Rental of Residential Property Act.

4. Assistance for Modifications

A major difficulty encountered by individuals with a disability, in particular, is that their ability to find affordable housing is often severely constrained by the fact that the residence must be accessible as well. While accessibility features are not very costly when these are incorporated into new residences at their design and building stages, modifications to existing residences can be prohibitive.

One way to address this problem is by improving the Residential Rehabilitation Assistance Program for the Disabled. The federal Task Force on Program Review pointed out that: "RRAP could be a cost-effective alternative to social housing programs, particularly if it is

Table 14
Adequacy of Shelter Allowance
British Columbia
Five Hypothetical Families
1989

	Total Shelter	Current Ceiling	Shortfall $[1]	Shortfall %[2]
Single male Bachelor	$403.06	$250	$153.06	61%
Single parent Son (age 5)				
One bedroom	$476.59	$412	$64.59	16%
Two bedroom	$598.18	$412	$186.18	45%
Couple				
One bedroom	$476.59	$412	$64.59	16%
Single parent Son (age 16) Daughter (age 14)				
Two bedroom	$598.18	$486	$112.18	23%
Three bedroom	$671.18	$486	$185.18	38%
Two parents Daughter (age 5) Infant (age 6 months)				
Two bedroom	$598.18	$526	$72.18	14%
Three bedroom	$671.18	$526	$145.18	28%

[1] Shortfall $ is total shelter less current ceiling.

[2] Shortfall % is shortfall $ divided by current ceiling.

Source: Social Planning and Research Council of B.C.
Regaining Dignity 1989. Vancouver, April 1989, p .25

targeted to those same households who would create a demand for social housing if they were to move. The program is a far less costly form of assistance that allows low-income households to improve their housing conditions while remaining in their own dwellings."[30]

The RRAP for the Disabled needs a boost in funding so that it can help more people. These funds can be recovered if given out in the form of a low- or no-interest loan. The program could be more widely advertised to inform potential beneficiaries of the available assistance.

A recent change to federal tax provisions will also help individuals offset the costs associated with costly modifications. The *Income Insecurity* study pointed out that costs incurred for accessibility modifications to the home are now recognized as an allowable medical expense. The problem with this arrangement is that the medical expenses credit is a non-refundable tax credit. This means that it provides no assistance to persons too poor to pay tax. While the new tax provisions are a positive initiative, they will be of limited value to many individuals who require assistance with costly home renovation.

Support Services

"Support services" refer to a range of services that enable individuals to live independently in the community. These include attendant care, homemaker services, respite care, and life skills training.

Support services have not been called "home supports" in this study because these services should be made available in any environment in which they are required. They should be provided in the home, workplace, educational institution, training facility, recreation facility — in short, wherever they are needed by the person with a disability.

The most immediate problem in developing a range of affordable housing options is the lack of community-based support services. In moving from congregate care to more natural environments, a fundamental shift in the delivery of services is required in which these are provided through independent auspices rather than as a feature of the home itself.

The proposed separation of support services from the residence would mean that persons with a disability would not be forced to live in a particular home simply because it was the only way to obtain the required services. Individuals would be free to move to the accommodation most suited to their needs in terms of cost, location, social

networks, access to transportation, and other amenities without losing the necessary supports.

If, however, support services are not attached to the residence, it is imperative that these be developed in conjunction with various housing options. Without the accompanying supports, there are really no options for community living.

The separation of housing and support services is predicated upon a close working relationship among all departments responsible for the funding of community-based living arrangements. There must be a more coherent planning process for social housing starting right at the federal level. A federal/provincial working group might be struck to consider the issue of separating the delivery of support services from the establishment of affordable housing and ensuring that both are developed in a parallel fashion.

The support services would have to be significantly different from the ones currently in place. As previously described, these have not been particularly responsive to individual need. Efforts to improve the delivery of services would have to ensure that these are demand-responsive. Homemaker services and attendant care, for example, must be available at the times and in the places where these are required by the individuals they were set up to serve.

In addition to problems concerning control of services and their capacity (and willingness) to respond to demand, there are difficulties arising from current funding arrangements. The first problem relates to the level and adequacy of funding; there are simply not enough services available especially in rural areas of the country and in smaller communities.

Several funding options that might address these problems are considered below. These options include: 1) the redirection of CAP/EPF funds; 2) expanded use of CAP; 3) changes in EPF funding; 4) changes in funding provided under CMHC; 5) new cost-sharing arrangements; 6) individualized funding; and 7) enhanced funding for family supports.

1. Redirection of CAP/EPF Funds

One solution to the supply shortage is the redirection of funds allocated under Extended Health Care Services. The monies that would have gone toward the support of services in Type 1 and Type 2 residences

could be redirected toward community-based support services that are detached from residences. Funders may resist the proposed move away from Type 1 and Type 2 residences toward more detached service arrangements on the grounds that there are economies of scale associated with the provision of group care. It is generally cheaper for one person to supervise four persons on the same premises than at four different locations.

It is possible, however, to "cluster" resources. For example, services are clustered when they are delivered from a core area within a housing project. Supported units that are served by a core nucleus of services or by geographically designated support services do represent a form of economy of scale. This feature need not be lost entirely if housing projects are properly designed.

Another important factor is the possibility that economies of scale are not being achieved through Type 1 and Type 2 residences. There may be excess expenditures in supporting these homes; the level of care provided may exceed the needs of many residents. Yet they must remain in these facilities because there is no other option. In effect, there may be many situations of "over care" in which individuals receive a relatively high level of support whether they need it or not.

The province of Ontario recently formed an interministerial task group composed of representatives from the Ministry of Community and Social Services, the Ministry of Health, the Office for Disabled Persons, and the Office for Senior Citizens' Affairs. Its mandate is to examine existing funding arrangements for the provision of support services and to determine ways in which these might be funded on the basis of what individuals actually need rather than according to the facility in which they are placed. This needs-based assessment approach may result in a more effective use of dollars that would be tied to real need and not to the cost of a facility or structure. A number of specific costing options are being considered by the task group at this time.

It may not always be possible to move away from CAP/EPF interface funding. Many individuals with a disability, especially those with a mental handicap, may require the more extensive forms of assistance provided through Type 1 and Type 2 facilities. If the services are not separated from the residence, it is important to find some way to overcome the problems associated with congregate forms of care.

One possible solution is to involve the residents as voting members on the committees and boards responsible for the operation of the

home. Where necessary, an associate member who would not hold actual membership in the sponsoring organization could be assigned to the voting members to help them participate on those boards and committees. This type of arrangement would at least provide a structure that embodies the ideals of inclusion, citizenship, and self-determination.

2. Canada Assistance Plan

The welfare or residual orientation of the current delivery system is another problem that must be addressed. Consumer groups, in particular, have noted that some provinces provide support services such as attendant care and homemaker services. A person has to be in need or likely to be in need to qualify.

This requirement creates difficulties for individuals for whom these services are essential. These services may be as critical as health care in terms of their importance to daily living. By virtue of this fact alone, they should be universally available to individuals with a disability.

In a strictly traditional sense, the Canada Assistance Plan is not an appropriate mechanism to support a universal service. Under the assistance provisions, service delivery is targeted toward those who qualify on the basis of a provincially administered needs test. Services funded under the welfare services provisions of CAP are cost-shareable only for those who qualify according to a needs or an income test. In short, CAP is a more targeted form of funding that does not support the delivery of services to the general population.

There is, however, a quasi-universal component to CAP that is found under the welfare services provisions of the Plan. More specifically, these provisions allow for the cost-sharing of services to members of a designated target group. The target group must consist of individuals likely to be in need and this likelihood is based primarily upon levels of income.

This means that the CAP mechanism is elastic enough to allow the provision of services to designated *populations*. As previously indicated, a significant outcome of the recent Federal/Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities was the agreement to change the likelihood of need policy to facilitate cost-sharing under the welfare services provisions of CAP. When individu-

als require services that are disability-specific, such as attendant care, they will be considered as persons likely to be in need.

The federal government is currently developing guidelines for interpreting this decision. In the meantime, some jurisdictions such as New Brunswick, Saskatchewan, and the Northwest Territories have indicated that it is too soon to know precisely how this agreement will translate into practice. Alberta, by contrast, has modified its income testing procedure, which is no longer considered necessary now that individuals with a disability can be classified as a "community of need." Quebec will continue to provide services to persons who are disabled on a universal basis.

The outcome of the Federal/Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities will have limited impact in Ontario as a province that does not generally charge for services related to disability. Newfoundland determines eligibility on the basis of an enriched needs test and will likely continue this practice. Nova Scotia has indicated that it may no longer require regular income testing of clients although the province may carry out sporadic needs testing to determine the profile of individuals being served.

While it is too early to assess the impact of this policy initiative, it nevertheless opens up the cost-sharing possibilities for a variety of support services intended explicitly for persons with a disability. The major obstacle will no longer be the welfare orientation of CAP. The problem will lie primarily in the willingness of provincial governments to spend the money on these services.

The February 1990 federal budget has cast a new light on cost-sharing arrangements. With the "capping" of federal sharing to Ontario, Alberta, and British Columbia, these provinces can claim that their hands are genuinely tied when it comes to new expenditures for initiatives under the Canada Assistance Plan.

Another important outcome of the Federal/Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities was an agreement to cost-share aids and devices on a universal basis to vocational rehabilitation clients. While only these individuals will benefit immediately, the agreement is significant for two reasons. First, it sets a precedent for the universal provision of special needs items to persons with a disability. Second, it proves that major improvements to the current service system can be effected within the context of current funding mechanisms.

3. Established Programs Financing

Among existing funding arrangements, the only other option for the universal financing of support services is through EPF, possibly by expanding the definition of what is considered to be home health care. Right now, this is fairly narrowly defined to refer to services of a health-related nature. The EPF option would require legislative or at least regulatory change in that homemaker and other non-health services are currently excluded from EPF coverage. It is of interest that health is defined so narrowly from a funding perspective even though it is conceptualized so broadly in the federal documents *Achieving Health for All* and *Mental Health for Canadians: Striking a Balance.*[31]

The disincentive in the EPF funding arrangement from the provincial perspective is that the financing of services through block funds means that the provinces would lose access to the 50-cent dollars provided under CAP. They would also have to spread their EPF dollars more thinly over a broader range of services. As previously explained, the EPF formula is calculated on a per capita and not a service basis. There is no increase in federal contributions to match provincially expanded services. In fact, the EPF contribution has decreased in real terms since the introduction of partial rather than full indexation of the funding formula.

There are several philosophical objections to this option. While individuals with a disability may require supports or assistance with daily living, most of them are not sick. A health-based mode of funding simply reinforces the illness mentality that, in turn, lends weight to the medical model for addressing everyday living situations. Services should be based on need and functional ability rather than on cause of need.

Another problem may arise from an expanded definition of home care. While such a definition would make the service package more inclusive, it may exacerbate the portability problem in which essential services are attached only to the home and not to the other sites in which they may be required. In addition, an expanded definition of home care would not be a desirable option unless there were new dollars attached to cover the extra services. Finally, EPF has been particularly vulnerable to federal cutbacks, making this option undesirable from the perspective of the provinces and territories.

4. Canada Mortgage and Housing Corporation

Yet another option for the cost-sharing of the staff support function is to encourage CMHC to expand its definition of what is cost-shareable under social housing. As previously explained, the "social" component of non-profit housing projects is no longer considered at the federal level as a shareable cost. Yet social housing projects incur additional costs by virtue of the fact that they have been set up to assist individuals with special needs. While there has been some leverage in certain provinces that have funded social costs, the 100-cent dollars they have to pay is a major disincentive to supporting this type of arrangement.

It is unreasonable to expect federal and provincial bodies responsible for housing to pay the cost of support services such as homemaker assistance, life skills training, or attendant care. However, it is reasonable to expect that a certain amount will be required for the operation of the project (e.g., for a project manager or supervisor) apart from the costs associated with the provision of specialized services.

It is unlikely, however, that housing bodies will want to pick up the tab for a function that may ultimately reduce social service costs in the budget of another ministry. Current administrative mechanisms provide no reinforcement for a process in which overall spending might be reduced. There is no "glory" for the department that puts out extra funds to save dollars for another department. When it comes to spending, each funding body is concerned with its own interests — its own bottom line — rather than the ultimate objective of the public expenditure.

5. New Cost-Sharing Arrangements

Another possibility for improving the availability of support services is the introduction of new cost-sharing arrangements. These do not necessarily require additional dollars but may instead redirect current expenditure.

Any new form of cost-sharing arrangement for support services should seek to overcome the weaknesses inherent in the current system. Ideally, funds would be provided on a universal basis for persons who require disability-related services rather than on the basis of income levels.

A new fiscal arrangement for support services would involve

either a block-funded or cost-shared mechanism. Various cost-sharing arrangements have inherent problems that should be noted. The disadvantage of block-funding, in particular, is that there is less control over federal funds once these flow into provincial treasuries. However, receipt of these funds might be made contingent upon the implementation of standards as exemplified by the criteria set out in the Canada Health Act. Funds would be directed only toward services that promote the principles of inclusion, citizenship, and self-determination.

A major problem with CAP is that 50-50 cost-sharing treats provinces and territories as though they were fiscally equal even though they all have different financial capacities. If a new funding mechanism is sought, consideration should be given to the ability-to-pay component through differential cost-sharing. Another option is to supplement a standard cost-sharing agreement with a special appropriation to economically weaker provinces to assist with the start-up costs of expanded support services.

While changes to current funding arrangements may ensure that the required services will be in place, these improved funding mechanisms will not necessarily promote self-determination. One means of directing more power to the consumers of service is through individualized funding.

6. Individualized Funding

Individualized funding involves the direct transfer of dollars to individuals. These funds represent the combined total of their basic needs (e.g., food, shelter, clothing, utilities) and special needs (e.g., transportation, medication, and purchase/maintenance/repair of essential equipment). At the current time, welfare systems provide funds for basic needs. Special needs are approved at the discretion of the welfare department and are provided in the form of a particular item or a service purchased on their behalf.

Chapter Three on Funding Sources pointed out that, with the exception of cash payments for basic needs, most federal transfers in respect of persons with a disability go toward the support of services. These are made available at the discretion of the sponsoring agency. There have been calls for a shift from funding the supply side of the equation toward funding the demand side of the equation — i.e., from

the services to the persons who require these services. They would then be free to purchase the services that best suit their needs.

Individualized funding is predicated on the assumption that there are, in fact, services to buy and that the only drawback is the individual's lack of funds or purchasing power. Yet all too often the required services are simply not available to purchase.

The counterargument, which is grounded in economic theory, is that services will spring up in response to demand. If there are dollars to be spent, then the service will be created. The implications of this route of service delivery are profound; it may inadvertently encourage a private market approach to the delivery of human services.

Yet the ultimate check and balance to the private mode of delivery is the consumer who virtually becomes the employer of the service provider rather than a benign recipient of service. There are obligations that an employer must assume as well. One of the unresolved issues is whether governments that provide individualized dollars should include an additional amount to cover the Unemployment Insurance and Canada/Quebec Pension Plan contributions that the person with a disability "cum employer" would have to make.

From a technical perspective, the calculation of basic living costs such as food, clothing, and shelter is a straightforward task. The costs associated with the purchase, maintenance, and repair of certain items such as technical aids, communication-related devices, work-related equipment, mobility devices, or prosthetic appliances can be readily calculated as well. The costs of attendant care and homemaker services are also relatively easy to determine (e.g., number of hours of service required x hourly rate plus a certain percentage for benefits).

It is a more difficult task to individualize dollars for "soft" services such as helping people prepare for and find employment. The cost of these services depends upon many factors including the total number of clients, staff/client ratio, and the fact that needs and abilities will likely change as a result of the service.

Despite the difficulties that may arise in the soft service calculations, it is entirely possible to support individualized funding plans within current funding structures. The assistance provisions of the Canada Assistance Plan, in particular, allow for the payment of: 1) basic needs, 2) special disability-related items such as medications and equipment, and 3) prescribed services. The latter are prescribed by regulation under the Canada Assistance Plan and include rehabilitation services, homemaker services, and counselling.

Technical difficulties may arise in relation to the cost of services that are not included under the assistance provisions. For example, home health care is funded through the EPF block. EPF dollars are used exclusively to finance services and not individuals.

In general, the more extensive the health-related needs, the more difficult it is under current arrangements to individualize the dollars. For many individuals, this limitation would not affect their individualized funding schemes. They already have access to generic health services as do all other Canadians and would not need to purchase these services.

To individualize dollars for those persons with extensive health-related needs, an agreement would be required in which the health department reimbursed the social services department for the component of cost represented by home health care. (In some cases, CAP funding is paying the costs of health-related items for eligible individuals and for non-EPF health care costs in long-term residential care facilities; the dollars are therefore already individualized.)

Another technical problem associated with individualized funding relates to the requirements under the assistance provisions. Applicants would have to qualify for individualized funding on the basis of a needs test. There are many objections to the needs test including the fact that it is both intrusive and exclusive (i.e., it eliminates individuals who do not qualify on the basis of a budget deficit). Philosophical objections aside, it is likely that the majority of persons with a disability would qualify for this assistance because most have low incomes and many incur high costs arising from their disability-related special needs.

The real issue is not so much the technicalities of the funding. If there were true interest in this approach, there would always be a way of working out the administrative difficulties. The real issue is the extent to which governments feel that costs will get "out of hand" if individuals were to be fully reimbursed on the basis of their real needs. At the current time, their needs fall far short of being met because special needs items are provided in a discretionary manner and there is a serious shortage of many services. A sincere attempt to redress this problem would have obvious cost implications.

It is important, however, to temper the concern about higher costs with the reality that some costs may decrease as a result of individualized funding. For example, if effectively implemented, this type of funding arrangement might reduce the costly overservicing of needs

and the funding of expensive service options. Often, extra costs arise because individuals did not receive the appropriate assistance in the first place (e.g., relatively inexpensive dental work can become very costly if not performed when required). If individuals had more control over the dollars expended on their behalf, there would likely be a shift toward less costly, more natural forms of support.

Furthermore, the availability of equipment and support services at places of work made possible through a system of individualized funding could promote participation in the paid labour force. Individualized funding may help reduce unnecessary dependence upon welfare and other programs of income support.

Another issue to consider with respect to this form of funding is whether governments will want to send monies to individuals without tight control over how these dollars are spent. Right now, direct payments are made in the form of welfare cheques. Concerns over improper spending and fraud (concerns that various studies have shown to be exaggerated[32]) would likely be amplified if additional monies were sent to individuals for the purchase of special needs items and services as well.

A possible compromise might be that governments agree to give the dollars that have been designated for a person's service needs directly to the various agencies or programs on the individual's behalf — which, in effect, is what is already happening. The result is that the concept of individualized funding essentially becomes a process of individualized accounting. The person would still receive no direct funds to purchase the required services and would have no control over their quality.

An important development in relation to individualized funding should be noted. The recent Federal/Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities supported the concept of direct payments to individuals. The new agreement under the Vocational Rehabilitation of Disabled Persons Program will explicitly recognize individualized funding for services such as attendant care and interpreters. It is possible that this outcome will set a precedent for more widespread use of this form of funding.

7. Family Supports

One of the pressing problems earlier identified is the lack of supports to assist families caring for dependents with a disability. Funds always seem to be available when it is necessary to remove an individual from the family because it can no longer cope with financial and psychological stresses. Yet there are rarely enough funds to support less costly, more natural family arrangements.

Supporting families to care for children with a disability is a generally accepted philosophical objective (even foster family arrangements are usually seen as preferable to group home care). The issue becomes more controversial when considering the option of parental care for individuals with a disability who are older than the traditional adult age of eighteen.

Many adults with a disability reject the family mode of care. Some have experienced overprotection and even neglect and abuse in these arrangements. Others object on philosophical grounds. They simply feel that living with parents beyond the socially accepted adult age is not a desirable option and should therefore not be supported.

Families caring for a person may worry about the individual's limited opportunities for independence as well as the stability of the arrangements. If the primary caregiver falls ill or dies, then the person with a disability may be left alone without any support. This is why many families agree to place their relative in a group home even though they are aware of the shortcomings of this housing option. At least the person with a disability will be linked with a network ensuring that physical needs are met.

The option of living with parents need not be a permanent solution but rather a choice that is available when appropriate and desirable for all family members. For some persons, living with families may be an alternative or back-up for short periods of time.

It is not the responsibility of governments to determine what is best for individuals and families. However, it *is* the responsibility of governments to remove impediments to natural living arrangements and to support these arrangements. There are three major forms of support that can be provided to families: cash assistance, provision of goods, and provision of services.

Cash assistance is currently made available to the parents of a child with a disability in the provinces of Newfoundland, Nova Scotia, Prince Edward Island, Quebec, and Ontario. The amount of assistance

(up to a designated maximum) is generally determined on the basis of family income and need.

Quebec, by contrast, offers a "universal" benefit to parents caring for a child with a severe disability (medical certification is required). While the benefit is automatically provided in the presence of disability and not according to income, many families require additional financial assistance to offset high disability-related costs.

Recognition of these extra costs through the tax system is another form of financial assistance. The disability and medical expenses credits already do that to a certain extent. However, there are two major problems with these credits. The first is that there are many expenses incurred by families that are not "deductible" within the current credits. The cost of respite care is not an allowable medical expense. The second problem arises from the fact that the disability and medical expenses credits are non-refundable. As a result, they are of no value to individuals and families too poor to pay tax. If they were made refundable like the child tax credit and sales tax credit, the disability and medical expenses credits would greatly help low-income households.

Most provinces assist families by providing or contributing to the costs of a range of goods and services. Alberta, for example, has the Handicapped Children's Services Program — a broadly interpreted program of assistance for families that reimburses disability-related costs. The extent and type of assistance is determined by a caseworker on a discretionary basis.

In 1989, British Columbia introduced its At Home Program to provide assistance with health care services and supports to parents caring at home for a child with a severe disability. The program makes available to eligible families a variety of goods and services including health care, medical equipment and maintenance/repair costs, drug coverage, dental care, medical transportation, hearing aids, and respite care.

While other provinces and the territories provide support services, families have too often indicated that these are inadequate. To make parental care a secure support option, substantial improvements in both the availability and quality of services are required.

However, the difficulty of linking service to income applies here as well. Services that are provided to all families regardless of income are not eligible for cost-sharing. Two possible solutions to this problem are: 1) to stretch the welfare services provisions of CAP so that parents

caring for children with a severe disability would automatically qualify for service as a target population of persons likely to be in need, and 2) to seek new forms of cost-sharing to support these services. Funds could be obtained through their redirection from costly institutional care to less expensive, more natural forms of support.

PERSONAL SUPPORTS

Personal supports are the third essential component of disability-related services. "Personal supports" refer to three different but related forms of support: personal support networks, brokerage, and advocacy. Of all components in the disability-related service system, personal supports are usually the weak link — in some cases, the missing link — in the chain.

Personal Support Networks

"Personal support networks" are the family and friends who are genuinely concerned about and committed to ensuring an individual's well-being and autonomy. Members of the network provide affection, emotional support, companionship, and caring.

The *Community Living 2000* document defines personal support networks in the following way:

> The idea of a personal support network is really quite simple — a group of people upon whom an individual depends — family, friends, fellow students, co-workers, members of the congregation, bowling partners, and so on. The network of people who ask us questions, give advice, act on our behalf, invite us out, give us leads for jobs, help fix up the basement; things which are freely given as part of living, not as an activity for which people expect to be paid.[33]

For many people, these natural networks of support are already in place. Others, however, have been rejected, overprotected, or abused by relatives. Many have been separated from family members and friends after many years in an institution. These persons may need help in developing or re-engaging their personal networks. An evaluation of

the Community Living Society in Vancouver found that only a minority of individuals represented in the study had families or other personal supports actively involved in their lives. The study also found that, without such supports, individuals' opportunities for friendship, advocacy, and assistance in making decisions about supports and service providers were limited.[34]

There has been experimentation throughout the country with various models of personal support networks. For example, the Community Living Society has stressed the importance of personal support networks in sustaining and enhancing the autonomy of the individual with a disability.

The model developed by the Calgary Association for Independent Living represents another approach to personal support networks. The association hired a personal support worker whose primary function was to help individuals build and nurture personal support networks. In yet another example, a woman with severe physical limitations was instrumental in developing the first Circle of Friends in the country. This was a group of committed persons who took genuine interest in her well-being, provided support and practical assistance, and intervened on her behalf when necessary.

Personal support networks can play several important roles in the life of a person with a disability. Members of the network can assist in locating the appropriate resources (and can advocate the development of such resources when these are not available). They can also act as a monitor of services to ensure that they are responsive to individual need.

In general, however, efforts to build and enhance personal support networks have been sporadic. There are few social agencies that systematically promote this form of natural support.

Brokerage

Brokerage is another important component of personal supports. The primary objective of brokerage is to enable persons with a disability to participate fully in the community.

The role of the broker is to assist individuals identify the resources and supports most appropriate to their needs and to gain access to these goods and services. The broker provides essential information to help individuals and their networks make informed

choices. It is not the role of the broker to replace the personal support network or to act as an advocate (described below). Rather, the broker is a mediator or bridge between persons with a disability and the providers of required goods and services.

There are several projects throughout the country that provide brokerage. The most well-developed example is the Community Living Society (CLS).[35] The brokers are employed by and accountable to the CLS. This arrangement helps maintain autonomy from government pressure to influence their actions.

However, brokers can be truly independent only if they are hired directly by the individuals on whose behalf they are acting. The problem with this ideal model is that most persons who need brokers cannot afford the hiring costs; many are recipients of social assistance. Ideally, provision for brokerage should be made by adding the costs of the service to the welfare cheque — that is, by giving individuals the dollars they require to purchase this service.

The notion of including service costs in the welfare cheque can be linked to the concept of individualized funding earlier described. The cost of the broker would be one more item added to basic living needs such as food, shelter, clothing, personal allowance, disability-related equipment, and essential services such as attendant care.

The alternative to demand-side funding of the brokerage service (giving individuals the money to pay for the service) is supply-side funding (supporting brokerage as a service attached to a non-profit agency). Even if funding is derived from a government source, the separation of the brokerage function from the funder through accountability to an outside agency helps protect the independence of the service.

Advocacy

Non-legal or social advocacy is the process of "defending, recommending, supporting or speaking on behalf of another person"; of "speaking out on behalf of others with vigour, vehemence and commitment using non-legal resources."[36] The objectives of social advocacy are to promote respect for the rights and freedoms of the persons served by the advocates; to ensure that these rights are protected; to assist them receive the health care and social services to which they are entitled; to help individuals lead lives that are as independent as possible; and to

protect vulnerable individuals from financial, physical, or psychological abuse.[37]

While non-legal advocacy is especially important for persons living in congregate care facilities, it can be of assistance to all individuals. For example, personal goals may at times clash with family expectations. It is therefore essential for all persons, especially those who have difficulty speaking on their own behalf, to have access to an independent source of support that can help protect their interests.

There are several models for the funding of advocacy services. A recently conducted Review of Advocacy Services for Vulnerable Adults stated its preference for the shared advocacy model, predicated upon the sharing of responsibility for advocacy services among governments, volunteers, and community groups.[38]

These groups would be encouraged to develop programs to meet the needs of the communities they represent. The advocate would be available to assist individuals living in the community as well as those in institutions, facilities, and homes — in short, persons who are particularly vulnerable to misuse of power, neglect, or abuse.

The Review proposed that advocacy services be structured so as to qualify for cost-shared dollars under CAP. The difficulty is that this funding arrangement may give rise to some of the same problems associated with other CAP-funded services. For example, the funding potentially excludes certain persons on the basis of their income.

Another option is to provide individual advocacy services through independent living centres. There are currently ten such centres in the country; another ten are in varying stages of development. While each is operationally different, they all seek to embody the principles put forth by the independent living movement: consumer control, community responsiveness, integration, non-profit funding, and cross-disability representation. (Despite their stated concern for all disabilities, the centres have not been actively involved in representing the particular needs or interests of individuals with a mental handicap.)

In addition to personal advocacy, independent living centres are involved in peer support, information and referral, independent living skills development, and research and resource development. The extent to which individual centres are engaged in each of these functions varies widely and depends upon local community needs as well as the funding base (e.g., funds from the local United Way; provincial ministry grants for a consumer-controlled attendant care service).

The current network of independent living centres, including the umbrella national office, is funded through a special grant from the Department of Health and Welfare. One of the problems that the centres may face in seeking ongoing CAP funds is that activities like advocacy are not cost-shareable under the welfare services provisions of CAP. However, services considered to be counselling, casework, referral, and research do qualify. It is possible that the existing definitions and provisions could be sufficiently stretched to accommodate the funding of these centres.

There is still a problem with CAP funding. Dollars provided under the welfare services must flow to *services*. Yet independent living centres have tried to avoid becoming traditional service providers. They are concerned that the role of direct service provider may detract from the core functions that the centres have been established to support.

These core functions are not social services that address personal problems. Rather, they are activities that enhance and promote the ability of individuals with a disability to participate as full and equal members in the community. They are functions that promote citizenship.

Because of the unique focus of independent living centres, it may be more appropriate to support their core functions through "citizenship dollars" from the Secretary of State. There is precedence for this proposal: Native Friendship Centres provide various types of assistance and support for native Canadians living in urban areas of the country. The purpose and activities of these friendship centres appear to be analogous to those of the independent living centres.

In 1988, the federal cabinet approved a permanent mandate for Native Friendship Centres with assured funding (subject to Treasury Board approval). Prior to this time, funds were provided on the basis of a five-year funding plan. In the 1989-90 fiscal year, a total of $18,281,000 was paid to ninety-nine centres throughout the country. The monies are intended for core operating budgets although there are some funds for capital expenditures such as repair to a building or accessibility modifications. (It should be noted that, as a result of the February 1990 federal budget, this program will be cut by $900,000. The budget for 1990-91 will be $17,381,000. The database component will no longer be funded. Initiatives promoting the physical accessibility of the centres may be affected.)

Secretary of State dollars would help promote access to independ-

ent living centres and the natural supports that they provide. Their activities can be characterized more as citizenship functions than as services that individuals require to help them deal with a particular problem or compensate for a certain weakness. However, because the core funding would be in the form of 100-cent federal dollars rather than 50-cent cost-shared funds, there may be fewer dollars available on an aggregate basis. Nevertheless, the operating core budget can always be supplemented through other sources such as municipal or provincial grants, United Way funds, and CAP cost-shared funds if eligible services are provided.

Before concluding this discussion of policy options, a word about the Free Trade Agreement is in order. Under the Agreement, Canada and the United States have agreed to a provision known as "national treatment." This obligation requires both parties to accord the right of establishment and the right of commercial presence — i.e., to be represented in each others' market.

Chapter 14 of the Agreement deals with services. Education, day care, and health and welfare services are not "tradeable" between the two countries on a commercial basis. However, the Agreement does open the door to the private management of these services including adult residential care facilities. Concern has been expressed about the potential commercialization of these services as a result of the Agreement.[39]

SUMMARY OF POLICY OPTIONS

A number of policy options can be pursued to improve the availability and quality of disability-related housing and support services. First, more funds should be directed toward the provision of generic services. Public policy and expenditure should be assessed in terms of whether they take into account and are responsive to the needs of all individuals including persons with any type of disability.

In addition to generic services, there will always be a need for special disability-related housing and support services. The housing component of the equation can be supported through: (1) increased funding of non-profit and cooperative housing, and (2) increased assistance with the cost of housing in the form of an enhanced rent supplement program, a tax credit, a more adequate shelter allowance

within welfare benefits, and an enhanced Residential Rehabilitation Assistance Program for the Disabled.

Support services can be more readily funded by stretching the welfare services provisions of CAP to include persons with a disability as a target group for cost-sharing purposes. This would allow the flow of funds to these supports in an almost universal fashion rather than according to individual qualification on the basis of a needs test or income test.

Group homes can continue to be funded under CMHC for the physical structure and under Extended Health Care Services for services. However, the dollars intended for services should be tied to standards that promote the principles of inclusion, citizenship, and self-determination.

Individualized funding is another option for the support of disability-related housing and support services. The funds would go to the individuals who require the assistance rather than to the services. This funding option is possible under the assistance provisions of CAP.

Other sources, including CAP and Secretary of State citizenship dollars, can be tapped to fund personal support networks, brokerage, and advocacy.

Finally, new cost-sharing arrangements can be sought for the support of disability-related housing and support services. While it may be difficult to obtain new dollars in the current climate of fiscal restraint, it *is* possible to "release" dollars by directing funds away from expensive, institutional forms of care to more natural housing arrangements with support services made available in the community.

Conclusion

Most persons with a disability are poor. Their poverty makes it difficult, if not impossible, for them to purchase decent housing or the support services they may require as a result of their disabling condition. Many rely upon group homes and residential facilities that are of questionable quality; they are basically poor places.

There are ways to reduce reliance upon these poor places. There are ways to change these poor places. This study puts forth options for enhancing the quality and increasing the availability of disability-related housing and support services. Improving housing and support services is critical because it is a means toward achieving something more fundamental: ensuring that persons with a disability are treated with dignity and respect — as full and equal participants in all aspects of Canadian society.

Notes

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2. A. Maslow. *Motivation and Personality* (New York: Harper, 1954).

3. Quote is from film entitled *And After Tomorrow*, 1986. Available from Health and Welfare Canada.

4. For a discussion of financial assistance to families, see Torjman, *Income Insecurity*, pp. 55-60.

5. For a discussion of tax provisions related to disability, see Torjman, *Income Insecurity*, pp. 61-69.

6. *COPOH's Preliminary Position on Fiscal Arrangements Affecting Disabled Canadians* (Winnipeg: Coalition of Provincial Organizations of the Handicapped, November 1987), p. 40.

7. See Recommendation #241 in *Transitions*. Report of the Ontario Social Assistance Review Committee (Toronto: Queen's Printer for Ontario, 1988), p. 481.

8. Information provided by a representative of the Advocacy Resource Centre for the Handicapped (ARCH).

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10. For a discussion of the "near poor," see: D. Ross and R. Shillington, *The Canadian Fact Book on Poverty 1989* (Ottawa: Canadian Council on Social Development, 1989), pp. 65-70.

11. C. Senn. *Vulnerable: Sexual Abuse and People with an Intellectual Handicap* (Toronto: The G. Allan Roeher Institute, 1988).

12. *You've Got a Friend: A Review of Advocacy in Ontario* (Toronto: Queen's Printer for Ontario, 1987), p. 56.

13. *COPOH's Preliminary Position on Fiscal Arrangements Affecting Disabled Canadians*, p. 21.

14. *Welfare in Canada: The Tangled Safety Net* (Ottawa: National Council of Welfare, November 1987), pp. 99-108.

15. *Obstacles: Report of the Special Committee on the Disabled and the Handicapped* (Ottawa: Minister of Supply and Services Canada, 1981), p. 4.

16. *Community Living 2000: A Time of Change, A Time of Challenge* (Toronto: Canadian Association for Community Living, 1987), p. 4.

17. *Transitions*, p. 505.

18. *Transitions*, p. 463.

19. The Honourable Jake Epp, Minister of National Health and Welfare. *Mental Health for Canadians: Striking a Balance* (Ottawa: Minister of Supply and Services Canada, 1988).

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